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Living with Uncertainty: The Impact on Breast Cancer Survivors and Their Intimate Partners

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Living with Uncertainty: The Impact on Breast Cancer
Survivors and Their Intimate Partners

by

Kimberley D. Dockery

A Dissertation Presented to the
School of Humanities and Social Sciences
in Partial Fulfillment of the Requirements for the Degree of
Doctor of Philosophy.

Nova Southeastern University

2014

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by

Kimberley D. Dockery

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Nova Southeastern University
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This dissertation was submitted by Kimberley D. Dockery under the direction of the chair of the dissertation committee listed below. It was submitted to the School of Humanities and Social Sciences and approved in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Family Therapy at Nova Southeastern University.

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TABLE OF CONTENTS

Acknowledgments.....	iv
List of Tables.....	ix
Abstract.....	x
CHAPTER I: INTRODUCTION.....	1
Uncertainty of Cancer.....	4
Five-Year Survival Milestone.....	5
Expanding Survivorship and Quality of Life.....	6
Quality of Life Changes and Treatment in Survivorship.....	7
Researcher/Writer Bias and Assumptions.....	8
Purpose and Significance of this Study.....	10
Overview of the Chapters.....	12
CHAPTER II: REVIEW OF THE LITERATURE.....	13
Breast Cancer Survivors and Families.....	16
Mental Health and Cancer-Related Stress.....	19
Family Support and Communication.....	21
Managing Possible Recurrence.....	23
Quality of Life.....	24
Medical Family Therapy.....	26
A Postmodern Social Constructionist Lens on Cancer Survivorship.....	28
Psychosocial Support and Interventions.....	29

Why Examine the Couple’s Experience of Cancer.....	33
Importance of Lived Experience Narratives.....	35
Professional Research and Clinical Practice.....	35
CHAPTER III: METHODOLOGY.....	38
Social Constructionist and Qualitative Research.....	39
Phenomenology as a Method.....	41
Self-Reflection of the Researcher.....	43
Data Generation.....	43
Data Collection.....	44
Data Analysis.....	46
Trustworthiness of Data.....	49
Quality Control and Ethics.....	49
CHAPTER IV: DATA ANALYSIS.....	51
Description of Participants.....	52
Presentation of Themes and Analysis.....	55
The Shake: Impact of Illness and Survivorship.....	59
Initial Responses to Impact of Illness.....	59
Physical Responses to Impact of Illness.....	61
Changes in Intimacy.....	63
Emotional Responses to Impact of Illness.....	64

Pressing Through and Living Beyond Cancer: Support and Resources.....	67
Family and Friend Support.....	68
Psychotherapy and Support Groups.....	70
Oncologist and Medical Team Support.....	73
Self-knowledge Through Guided Research.....	77
Open Communication and Emotional Connection.....	79
Support of Relational Strengths.....	81
Spirituality and Faith.....	83
Making Meaning of Illness and Survivorship.....	85
Introspection and Reflection As a Couple.....	86
Celebration of Living and New Normal.....	86
Value of Time and Milestone Moments.....	88
Conceptualization of Breast Cancer.....	91
Acts of Kindness.....	91
Concluding Remarks.....	93
CHAPTER V: DISCUSSION AND IMPLICATIONS.....	96
Discussion of Study and Findings.....	98
Discussion of Categories.....	100
Emotional and Psychological Responses.....	101
Physical Responses.....	102
Financial Responses.....	103

Support and Resources.....	103
Strength as a Unit.....	105
Introspection/Reflection as a Couple.....	107
Implications of the Study.....	108
Strengths and Limitations.....	108
Validity and Reliability.....	110
Implications for Practice and Research.....	112
Implications for Practice.....	112
Implications for Research.....	115
Final Thoughts.....	117
References.....	118
Appendices.....	133
Appendix A: Cancer Survivor Consent Form.....	133
Appendix B: Significant Other Consent Form.....	133
Appendix C: Participant Interview Questions.....	137
Appendix D: Recruitment Letter.....	138
Biographical Sketch.....	139

List of Tables

Table 1: Super-Ordinate, Emergent, and Sub-Themes.....	58
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Abstract

This study explored the lived experiences of breast cancer survivors and their intimate partners. The research was informed by a social constructionist framework and phenomenological method of inquiry. While the body of literature on the physical, psychological and social health of breast cancer survivors is growing, only a few studies have focused solely on the lived experience of survivorship and the uncertainty of recurrence. This study explored the construction of meaning in the couples' context and experiences of surviving breast cancer, examining how breast cancer survivors make meaning of their survivorship in context of living with the fear of recurrence. The researcher investigated patients' and their intimate partners' experiences of survivorship to gain a better understanding of how their lived experiences affect their relationships to themselves and their significant other and how they cope with the uncertainty of recurrence. I conducted open-ended style interviews with breast cancer survivors and their intimate partners. Transcripts of the couple interviews were analyzed using interpretative phenomenological analysis. Emergent themes highlight the importance of relationships, resources, and changes in perspectives. Findings suggest that having a supportive intimate partner alleviates the impact of uncertainty on the couple's relationship. The study provided clinical implications for medical family therapists working with breast cancer survivors and for couples managing the challenges with survivorship and uncertainty.

CHAPTER I: INTRODUCTION

An individual is considered a cancer survivor from the time of cancer diagnosis through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience.

(The National Cancer Institute's Office of Cancer Survivorship, 2011, p. 29)

Being diagnosed with breast cancer can be a life-altering experience. It can occur without any warning and is accompanied by a sense of uncertainty. Undergoing the process of diagnosis, surgery, and treatment can be physically and emotionally grueling for a breast cancer patient and those close to her. When diagnosed with breast cancer, a woman realizes that her life has different meaning and will never be the same (Sadler-Gerhardt, Reynolds, Britton, & Kruse, 2010). The impact of uncertainty also leads to unpredictable outcomes, which can become either negative or positive in the lives of cancer survivors (Parry, 2003). Even though existing literature has included more research on long-term survivorship, uncertainty still remains a prominent theme in cancer survivors' narratives (Atkinson, 1995; Babrow, Kasch, & Ford, 1998; Crepeau, 2000; Katz, 1984; Parry, 2003). Unfortunately, research is limited regarding how cancer survivors manage the uncertainty and how the experience affects the entire family system (Lederberg, 1998; Oktay, Bellin, Scarvalone, Appling, & Helzlsouer, 2011; Sherman & Simonton, 1999).

An estimated 1,437,180 new cases of cancer will be diagnosed in the United States annually, and approximately 565,650 people will actually die from cancer (Ries, Melbert, & Krapcho, 2008). Even more alarming, an estimated 43.24% of people in the United States will be diagnosed with some type of cancer each year (Ries et al., 2008).

However, due to early detection and improved treatment options, the survival rate of breast cancer has increased in the United States (Ries et al., 2008). According to the American Cancer Society (2011), 12 million people are alive today after having some form of cancer, and the survival rate is increasing. When treatment ends, the patient and her intimate partner can begin a new chapter that is filled with happiness and hope, but also with uncertainty. The fear of uncertainty is quite common among cancer survivors and their families. Although a medical oncologist may tell the patient that the illness is gone or claim that the cancer is removed or there is no evidence of cancer, the possibility remains for it to recur.

Cancer recurrence is defined as the return of cancer after treatment and after a period of time in which no cancer was detected (American Cancer Society, 2011). According to the American Society of Clinical Oncology (ASCO, 2011), most recurrences can occur within the first five years after primary treatment. Frequent follow-up visits are recommended; however, the possibility of recurrence is a long-term concern for the patient and her family members. The ASCO also recommends that the patient have a postoperative plan, which suggests monthly breast self-examinations and physical exams with the patient's primary care physician every three to six months for the first three years, every six to twelve months for the following two years, and every year thereafter in addition to annual mammograms (ASCO, 2011).

While statistics from the American Cancer Society (2011) and the American Society of Clinical Oncology (2011) have provided readily available data on the rate of diagnosis and survivorship and have offered guidelines about after care treatment, the view is quite patient-centered and stems from a traditional medical model. The statistical

data provides a detailed overview of the specific types of cancer; the sex, age, and race of the patient; and even the patient's geographical location in the United States. It is important to note that the data leaves out a more multi-dimensional view of the patient's well-being, failing to provide information about the content of care or the families and loved ones who remain connected to patients during their journey.

Family members and loved ones can affect a patient's well-being and quality of life, positively or negatively (Firth, 2006; Julkunen, Gustavsson-Lilius, & Hietanen, 2009). According to Mehl-Madrona (2005):

No patient or anyone, for that matter exists independently of his or her immediate social network or the web of human existence. It is thus difficult, if not impossible, to heal at the deepest levels without addressing the social dimensions of a person's life. (p. 24)

A woman's experience of surviving breast cancer is not physically and emotionally isolated; therefore, it confirms that the lived experience of breast cancer is influenced by the context in which it occurs (Schmallinger & Sher, 2000; Thorne & Murray, 2000).

As a result, the family members, friends, and loved ones of the woman who has survived breast cancer vicariously experience the possible recurrence of the disease for her. Naturally, family members are concerned about the patient's health and follow-up appointments after her primary treatment of breast cancer. Female family members and friends may become especially vulnerable to the presence of breast cancer because of the increased cognitive awareness of their own health (Hasson-Ohayon, Goldzweig, Braun, & Galinsky, 2010; Lewis & Hammond, 1996).

The likelihood of the entire family becoming fearful of the patient's survival and the possibility of the loss of someone dear to them is quite common (Lewis & Hammond, 1996).

Uncertainty of Cancer

It is often stated that cancer is a family disease; but, medically, the focus is primarily on the breast cancer patient, often ignoring the context of the family (Lederberg, 1998; Oktay et al., 2011; Sherman & Simonton, 1999). If a woman's life is closely connected with others during this time of transition, her significant other, children, and other loved ones will also be affected by her experience. Taking into account the shared experience of breast cancer incorporates the key principles of systemic thinking, reflecting that experiences such as breast cancer recurrence affect the patient and her close relationships (Corbett, 2010; Oktay et al., 2011; Walsh, Manuel, & Avis, 2005).

The phrase, "Cancer is back" is not what the woman and her significant other would like to hear from their oncologist; but unfortunately, it is a possibility. Currently, there are 2.5 to 2.7 million breast cancer survivors living in the United States. According to the American Cancer Society (2011), as many as 10-20% of these women have already developed or will eventually develop a recurrence of breast cancer, which differs from other types of cancer. The risk of breast cancer recurrence varies across cancer survivors. Several factors can play a role, including age, inherited susceptibility, the stage of the original tumor, the type of original treatment, and other health factors. According to Devita, Hellman, and Rosenberg (2008), the United States recurrence rates in the 1980s and 1990s were reported as 8-19% following the tenth year of the woman's initial diagnosis and treatment. Within the early 21st century, the 10-year rates of recurrence

were reported as 2-7%, which shows recent improvements in treatment and an increase in survivorship (Devita et al., 2008).

Conversely, there are a growing number of survivors who have other challenges and do not receive adequate attention and support (Institute of Medicine, 2005; Rowland, Maritto, & Aziz, 2004).

According to a report published by the Institute of Medicine (2005):

Caregivers and family members often require, but do not receive, the respite health care, psychosocial, and financial assistance they need in meeting the many needs of cancer survivors in their lives and underscores the importance of using a family centered approach to service this specific population. (p. 67)

In other words, survivorship should not only include physical symptoms of recurrence, it should also take into account ongoing issues like psychosocial stressors and finances within the context of the family unit (Oktay et al., 2011). Research offers only part of the survivorship story and the lived experience of the patient and those connected to her.

Addressing the larger narrative can expand the story of surviving cancer and offer multiple perspectives. Because of advances in cancer treatment and care, accessing the stories of the increased numbers of families surviving breast cancer can offer more richness and meaning as well as contribute further knowledge to this topic.

Five-Year Survival Milestone

Currently, in the absence of other competing causes of death, nearly 64% of cancer patients are expected to live past the five-year survival milestone (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). During the 1970s, the long-term survival rate was less than 50%. Today, there are more than 12 million survivors in the United

States alone (American Cancer Society, 2011). Twenty-two percent of those cancer survivors are women who have had breast cancer (Ries et al., 2008). Approximately 23% of newly diagnosed breast cancer patients are women under the age of 50. The mortality rate of younger women has declined at least 3%—compared to older women at 2%—over the last 15 years (Bloom, Stewart, D’Onofrio, Luce, & Banks, 2007). Therefore, the number of breast cancer survivors is increasing with earlier diagnosis and improved treatment options, which fits accordingly with the American Cancer Society’s goal of promoting the long-term health of cancer patients (Demark-Wahnefried et al., 2005).

Because of those advances in survivorship, people are focusing more on the quality of life and long-term outcomes of cancer survivors. Cancer is no longer a word that people are afraid to speak of in public or even in their own homes. Clearly, researchers have become more involved in exploring the medical, emotional, financial, and relationship changes that may result from the life-altering illness. Current research now explores how patients manage to live with the possibility that cancer will return after they have reached the five-year milestone (American Cancer Society, 2011).

Expanding Survivorship and Quality of Life

One-third of breast cancer patients die from cancer (American Cancer Society, 2011); and for those who survive, it is almost impossible to be sure that the cancer will not return again. Research shows that for breast cancer survivors and their loved ones, managing this type of uncertainty can be extremely challenging (Oktay et al., 2011). When a patient and her family complete treatment, they typically anticipate getting back to their daily lives and starting to function as a *normal* family again. It is becoming clear that completing treatment is often the first step in the long journey following the initial

diagnosis and treatment. A new set of questions, issues, and even challenges might arise weeks, and even months, later for patients and their families (Geffen, 2010).

As the rates of cancer diagnosis continue to increase, the United States population will continue to be touched by this disease. While many people will not be diagnosed themselves, they will be connected to those who have a family member or friend diagnosed with some type of cancer. As we expand the meaning of survivorship, the wider perspective will offer researchers the chance to broaden and deepen their understanding of who is affected and who survives this disease. Furthermore, research that takes into account a broader meaning of survivorship can invite family therapists and researchers to look at how breast cancer impacts the lives and relationships of individuals other than the breast cancer survivors. In addition, research on survivorship can offer oncologists, nurses, and other health care professionals more insight to enhance shared family understanding, open communication, and offer coping mechanisms for those affected by this disease.

Quality of Life Changes and Treatment in Survivorship

Improvements in breast cancer detection, treatment, and survivorship have also led to some research in understanding the wide range of alternative forms of therapy that cancer patients have found useful. These alternative treatments range from the use of vitamins, herbs, and dietary/lifestyle changes to traditional/folk remedies (Ganz, Desmond, Leedham, Rowland, Meyerowitz, & Belin, 2002). Psychotherapy, or counseling, has also become more popular in the treatment of cancer survivors. According to Ganz et al. (2002), more than 13% of the women in their quality of life research study were currently utilizing counseling services, and others reported that they

had used psychotherapy in the past. On the other hand, 6% of women in Ganz et al.'s study were attending individual counseling services, and less than 1% were in couples or family therapy at the time of the study.

While only 5% of the active participants in Ganz et al.'s (2002) study reported that they were currently attending cancer support groups, 30% reported that they had attended groups as part of their illness experience. Cancer survivors in the study also reported using meditation and relaxation techniques, including breathing exercises and yoga. Lastly, the use of massage therapy and acupuncture made up a combined 12% of the reported alternative therapies for cancer survivors in the study (Ganz et al., 2002).

An exploration of the experiences of various breast cancer survivors suggests that younger breast cancer patients are more open to psychotherapy, spirituality, and changes in exercise and diet to work towards quality of life and survivorship (Broeckel, Jacobsen, Balducci, Horton, & Lyman, 2000; Burstein, Gelber, Guadagnoli, & Weeks, 1999). Because this area of knowledge is quite limited, family therapy researchers have to draw upon psychosocial, oncology, and nursing research to seek alternative understandings of coping mechanisms for survivors and their families (Sherman & Simonton, 1999).

Researcher/Writer Bias and Assumptions

Patton (2002) advises that “neutrality is not an easily attainable stance, so all credible research strategies include techniques for helping the investigator become aware of and deal with selective perception, personal biases, and theoretical predispositions” (p. 51). Therefore, it is important for me to address that I have an academic, professional, and personal interest in the topic of families' experiences of surviving breast cancer and

facing the uncertainty of recurrence. In this research study, I have three connected, yet separate, roles: those of researcher, professional, and family member.

As a researcher, I explored the patients' and intimate partners' experiences of survivorship and how those experiences affected their sense of self, their relationship, and their feelings of uncertainty. I gained a rich understanding about the different moments in the patients' experiences, such as the initial diagnosis by their oncologists and their health-related experiences with loved ones. I also captured any relational challenges during follow-up and remission and as a result of the presented possibility of recurrence.

As a professional, I work with patients and provide psychosocial support to loved ones dealing with a diagnosis of cancer. I hear stories of patients and their family members who are coping with the impact of cancer in their everyday lives, and it drives me to want to develop psychosocial programs and seminars that offer more collaborative therapeutic services for patients and their families.

Cancer has impacted my own family on several occasions. My paternal grandfather died of metastatic cancer when I started my masters' program eight years ago, and two of my paternal aunts died of breast and colon cancer. Cancer entered both my maternal and paternal families over 15 years ago. My experiences with cancer have shaped my personal and professional life journeys. My experiences help guide how I use the knowledge of my research in my personal life, helping to inform how my family makes cancer-related decisions and how I provide support to my loved ones. My hope is that my personal experiences will offer more understanding, respect, and care for couples who are experiencing this unique illness journey.

Purpose and Significance of this Study

Most research studies have used a quantitative inquiry to focus on the diagnosis of cancer and its impact among family members (Jacobsen, Donovan, Trask, Fleishman, Zabora, Baker, & Holland, 2005; Jacobsen & Jim, 2008; Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001). In addition, the research literature reflects a limitation in the understanding of how this illness is experienced in diverse families. While previous studies have outlined several themes for understanding the effects of breast cancer, most do not reflect the unique experiences and voices of the patients and their significant others. Instead, the researchers offer the reader a detailed interpretation of the questionnaires or surveys they used in their research. The study results offered the actual voices, stories, and experiences of those affected by breast cancer. Details of the lived experiences of families—as well as the valuable relational components of the cancer experience—are not found within current research studies. Pelusi (1999) notes that the voices of significant others are missing in the research literature. This study, through its phenomenological methodology, allowed those multiple voices to be heard.

The purpose of this study conveyed the experiences of those surviving cancer—to share their stories of survivorship and their experiences with the uncertainty of living with possible recurrence. The voices of the participants revealed meanings and the essence of the family experience of breast cancer (Moustakas, 1994). Corbett (2010) highlights the important differences between individuals' experiences of cancer versus the experience of the entire family. The author recognizes that the illness is the common factor within the family, although each member filters the experience differently (Corbett, 2010).

To get a clearer understanding of the lived experiences of those coping with breast cancer, it is important to delve into the uniqueness and depth of their experiences. Corbett (2010) emphasizes that while each person's voice is unique, there are common factors in the illness stories of survivors and their loved ones. Not every couple's experience of cancer will be the same, and each family might encounter cancer in different places in their lives. Therefore, the research questions that guided this study are the following: How does the survivor and their partner establish a clear vision of their lives when dealing with survivorship and the uncertainty of recurrence? How are couples making meaning and coping with those experiences in their lives? What role did psychotherapy and/or support groups play in their illness experience? Using a phenomenological inquiry can offer new understandings about the essence of couples' experiences when dealing with the effects of possible recurrence.

Additionally, this study offers insight into how couples' experiences of breast cancer survivorship and uncertainty can possibly help other couples, families, family therapists, oncologists, and other health professionals to develop helpful family interventions towards best practice and program evaluations. Research has shown that the ability to find meaning in the cancer experience may help couples and families cope better with the illness (Kissane, Maj, & Sartorius, 2011). This type of knowledge will make a significant contribution to the currently sparse literature in the area of survivorship and uncertainty. Although other disciplines have examined breast cancer and survivorship, as a family therapist and systemic thinker, I view it through a different lens. I see the woman and family surviving breast cancer as not simply a *patient* or *breast cancer survivor*, but as a mother, wife, or sister who is closely connected and engaged

with her family and other larger systems. In essence, I consider that the woman surviving breast cancer has probably dealt with very challenging moments in her life while simultaneously juggling relationships with her family members and friends (Corbett, 2010; Katz, 2003). My research study broaden conclusions made by previous researchers that guides research on special topics such as family resilience, interpersonal communication, and therapist-patient relationship in the area of cancer survivorship and medical family therapy.

Overview of the Chapters

In Chapter II, I review the existing literature and provide a snapshot of the lives of couples dealing with breast cancer survivorship and uncertainty. Chapter III, I describe the process of constructing this study and how phenomenological inquiry can be used to explore couples' experiences of surviving the illness and living with the uncertainty of possible recurrence. In Chapter IV, I present my analysis of the rich descriptions and meanings in the data, reflecting the multiple couples' perspectives. In Chapter V, I discuss the significance of this study and how its results can be useful to the field of medical family therapy.

CHAPTER II: REVIEW OF THE LITERATURE

Today, more people are living with and beyond cancer.

(CancerCare, 2012, p. 3)

Researchers and health care professionals now have a better understanding of cancer and how it affects the patient and her loved ones; but literature on long-term care, survivorship, and psychosocial needs is only just beginning to address the quality of life among survivors and their loved ones (Vacek, Winstead-Fry, Secker-Walker, Hooper, & Plante, 2005). Oncologists know that more women are living longer after treatment, allowing them to better understand the needs and concerns of breast cancer survivors. Health care providers have acknowledged the impact of the medical and psychological effects of cancer over the years, but recently, survivorship has been recognized as a distinct phase of the cancer experience (Hewitt, Greenfield, & Stovall, 2005). Recent advances in the knowledge of how women are living with and beyond breast cancer have led to developments in health care and support needs (Cappiello, Cunningham, Knobf, & Erdos, 2007). While these advances are welcomed, they also present an important issue that needs to be addressed: the support and care of the estimated two million women currently surviving breast cancer in the United States (National Cancer Institute, 2006).

Cancer survivorship is the experience of living with, through, and beyond breast cancer (National Coalition for Cancer Survivors, 2007). Women and loved ones living with and beyond breast cancer are dealing with special health care and psychological needs as a result of their initial cancer diagnosis (Cappiello et al., 2007; Hudson, 2005). Breast cancer patients report symptoms including, but not limited to, psychological distress, changes in sexuality, impaired cognition, fatigue, and decreased physical

functioning (Ganz, Greendale, Peterson, Kahn, & Bower, 2003). Although research has been conducted on the physical and psychological symptoms and the quality of life outcomes of women during and after breast cancer, much less has focused on the experiences of women who have completed treatment (Ganz et al., 2002; Knobf & Sun, 2005). During this particular time, women have reported feeling vulnerable, anxious, insecure, and in crisis (Ganz et al., 2002; Knobf, 2000).

The meaning of a cancer survivor's life and health is altered again because she has survived her diagnosis. Breast cancer survivors and their loved ones have not only battled the life-threatening illness, they have also needed to find a sense of wholeness, purpose, and hope for the future. The family may develop a new orientation toward life decisions or make changes in their values and goals. A couple with teenage children may wonder whether they will both attend their children's college graduations or weddings, or if they'll live to see their grandchildren. Even if the breast cancer survivor lives beyond cancer, she may be immobilized by fears of recurrence and have difficulty thinking about the future. Some couples and families make adjustments to their life plans that create challenges or even enhance their ability to move forward in their lives.

The narratives of families surviving breast cancer can provide the reader with details about the families' lived experiences. The rich descriptions can be seen as a window into the thought processes, emotions, and experiences of the patient's family members during the transition into survivorship. Phenomenological inquiry provide the opportunity for different families to share and make meaning of their experiences with their loved one's transition from breast cancer *patient* to *survivor*. Cancer's effects are not limited to the individual who is diagnosed; they impact the entire family (Corbett,

2010; Hewitt et al., 2005). The goal of this research study is to explore survivor and family narratives in order to provide more detailed accounts about this phase of survivorship and to increase the knowledge of family therapists about this growing population of healthcare consumers.

Vast attention is given to cancer research in our society; studies that originate from the nursing, psychology, anthropology, and public health disciplines can be found in scholarly journals. Surprisingly, clinical and qualitative writings, which provide richness in this topical area, are not readily available to practitioners in the field of family therapy. As a family therapist, I have a shared interest in the personal and unique experiences of people affected by breast cancer, especially during the phase of transition toward survivorship. I believe it is important to contribute to this body of literature in medical family therapy because there is no universal description of breast cancer survivorship. Despite the normative assumptions about breast cancer patients and survivorship, my hope is to orient myself within social constructionist paradigm to gain multiple ideas, views, interventions, and understanding of the families' experiences. Consequently, there is no set formula for treating and supporting this particular population, but my goal is to increase our understandings about the types of psychosocial support and educational interventions needed by families affected by breast cancer. Such interventions can provide family therapists a guide for creating ways to improve families' quality of life through dialogue and meaning that is constructed by their experiences and reality.

The following review of the literature provides an overview of recent studies offering more information about how families experience the transition from patient to survivor. Secondly, I address how families are managing the possibility of recurrence and

the accompanying adjustments to their quality of life. In essence, I address how medical family therapists can offer therapeutic support by utilizing a social constructionist framework, which acknowledges the possibility of multiple truths and realities in life after treatment. Finally, I address why it is important to study this area of cancer survivorship. I explore why the findings of the present study can help facilitate the delivery of resources that address the emotional, physical, interpersonal, and life functioning needs of breast cancer survivors and their loved ones and how we, as therapists, can bridge the gap in this unique area of study.

Breast Cancer Survivors and Families

The transition from breast cancer patient to breast cancer survivor has been described as a tumultuous experience for diagnosed women and their loved ones (Allen, Savadatti, & Levy, 2009). Despite having completed treatment, women experiencing this *re-entry phase* often have emotional and physical challenges when returning back to their *normal* lives (Allen et al., 2009). For example, women with breast cancer have to adjust to limited support from health care providers, as their frequent appointments change to follow-up appointments. The patients and their family members lose the close monitoring of symptoms that is connected to recurrence during typical treatment appointments and transition, instead, to the breast cancer survivor monitoring herself. Stanton et al., (2005) capture this readjusting period with a breast cancer survivor's statement: "Now, every little thing has me petrified! Any ache means that the cancer is back . . . but, then, I worry that, if part of my mind still believes that the cancer will come back, maybe it will" (p. 2608).

Some women in Stanton et al.'s (2005) study reported being more alert and cautious during this period because of the new responsibility it entails (Cordova, Andrykowski, Kenady, McGarth, Sloan, & Redd, 1995). Although free of cancer, women may become distressed over the loss of their medical team safety net (Allen et al., 2009). The fear of recurrence, uncertainty, and even worries about physical effects after the completion of treatment become normal responses for women surviving breast cancer (Hewitt et al., 2005).

The effects of the responses to cancer-related distress are not isolated to the individual with the diagnosis; the transition following the completion of treatment impacts the entire family. Rolland (2005) observes, "the impact of a diagnosis of cancer reverberates throughout the entire family system, leaving no one untouched" (p. 2584). Therefore, the needs of children, spouses, partners, and other loved ones should be considered and addressed. Family members who were present during treatment frequently provide personal care and emotional support for the duration of the cancer experience and, as a result, are significantly affected by the transition from treatment to survivorship (Hewitt et al., 2005). While research in this area is growing, the existing literature still does not provide an in-depth understanding of the survivor's and family's experiences of possible recurrence and the close monitoring of health, psychological distress, and support of family members that is part of the survivorship process (Allen et al., 2009).

Research studies conducted by the National Cancer Institute (NCI) found that comprehensive support services were offered to individuals after treatment through professionally led support groups in 18 different cancer centers throughout the United

States (Tesauro, Rowland, & Lustig, 2002). It was noted that no support groups were accessible for the loved ones of cancer survivors. Because family members were not designated support groups of their own, they were asked to join cancer survivor groups. The topics that were commonly covered within the support groups included concerns with intimacy, financial strains, fear of recurrence, changes in relationships, and stress management (Tesauro et al., 2002). Although the findings identified that supportive services exist, the research study did not clearly define details about when the support was given in the course of survivorship or whether the supportive services were valuable for the cancer survivor and her family (Tesauro et al., 2002). Current literature acknowledges that psychological distress is frequently reported among family members; however, there is less social support available to them (Hasson-Ohayon et al., 2010).

Policies have been implemented to provide support for the survivor and family members' needs through discharge plans, survivorship care plans, and lifestyle guidelines (Kissane, Bultz, Butow, & Finlay, 2010). For example, the survivor is given recommendations for how to enhance her overall health as a survivor and decrease the likelihood that secondary cancer will recur. The recommendations address weight management, diet, exercise, financial information, sexual functioning, work, parenting, and even relationship concerns (Kissane et al., 2010).

Survivorship becomes an important part of the cancer journey; it is, potentially, the longest transitional phase that survivors and their loved ones experience. The increasing number of survivors has led to improved efforts to promote more options that address patients' unique concerns and needs. The cancer care system has implemented various models of survivorship care from the medical and psychological lenses.

As a family therapist, I am drawn to efforts to understand any effects of cancer after treatment on the mental health and needs of survivors and their family members.

Mental Health and Cancer-Related Stress

The diagnosis of cancer can be described as one of the most stressful medical diagnoses for a patient to be given (Weisman & Worden, 1976). Data from several studies show that emotional distress can occur during diagnosis and treatment, as well as during survivorship (Epping-Jordan, Compas, & Osowieki, 1999; Golden-Kreutz & Anderson, 2003; Maunsell, Brisson, & Deschenes, 1992). Depressive symptoms were reported the most commonly among cancer patients during and after treatment (Golden-Kreutz & Anderson, 2003; Van't Spiker, Trijsburg, & Duivenvoorden, 1997). For those patients diagnosed specifically with breast cancer, the rates of depressive symptoms were the third highest among all cancer diagnoses (McDaniel, Musselman, & Nemeroff, 1997). Although cancer survivors might experience any major psychological concerns, they often only report distress and seem to adjust well over time (Stanton, Danoff-Burg, & Huggins, 2002).

Stress has been conceptualized in these studies as life events, stressors, or even perceptions of stress that require a person to make some type of adjustment (Golden-Kreutz, & Anderson, 2003; Maunsell, Brisson, Mondor, Verreault, & Deschenes, 2001). For instance, women might experience emotional stress as a result of managing complex decision-making, threats to their physical health, and their relationships with loved ones creates. Most survivors experience anxiety associated with the fear that their cancer might return after treatment ends, especially when an unknown physical symptom appears (Allen et al., 2009; Thewes, Butow, Girgis, & Pendlebury, 2004).

Research indicates that anxiety and stress are also quite dominant among patients, their partners, loved ones, and caregivers (Boyer et al., 2002; Grunfeld, Coyle, & Whelan, 2004; Hasson-Ohayon et al., 2010). Recent studies report that 10-20% of women with a breast cancer diagnosis meet criteria for anxiety disorders (Burgess et al., 2005; Dausch et al., 2004; Love, Kissane, Bloch, & Clarke, 2002). Fear of recurrence was most frequently reported as a psychological concern for women during their recovery period (Cappiello et al., 2007). In addition to fear and anxiety, survivors might also experience challenges with their physical appearance, sexuality, pain, and fatigue months or even years after treatment (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Leventhal & Shearer, 1989; Thewes et al., 2004).

Based upon the existing literature, it is clear that most breast cancer survivors have experienced psychological and cancer related distress. But the majority of survivors do not report any major psychiatric illness associated with their diagnosis and treatment. Therefore, the assumption that ending treatment is a milestone for survivors and their loved ones is not necessarily valid, because there are times that survivors and family members face challenges that can cause increased distress. Findings suggest that fear of recurrence is quite common and persistently reported by survivors. Polinsky (1994) found that 89% of 200 breast cancer survivors reported some thoughts of recurrence. Another similar study reported that the greatest concern among women after treatment was recurrence (Fredette, 1995). Clearly, some women are experiencing distress and fear while others are displaying remarkable resiliency (Allen et al., 2009).

Family Support and Communication

Overall, the many experiences that accompany breast cancer survivorship offer an opportunity to explore the effects of the transition process on both the survivor and her family members. Unfortunately, limited research has been conducted on narratives that explore how cancer survivors cope with uncertainty and manage the transitional phase towards surviving cancer as a family unit (Lederberg, 1998; Oktay et al., 2011; Sherman & Simonton, 1999). There still remains a need for families to have useful information that facilitates open communication among the survivor, loved ones, and providers of care.

Rolland (2005) states that “families enter the world of illness and disability without a psychosocial map. Because of this, appropriate clinical intervention, family education, and national policies to support these families are lacking” (p. 2584). Corbett (2010) shares a similar viewpoint, stating that families should have “ongoing, circular communication among the provider(s), the patient, and the family” (p. 42). From a systemic perspective, responding to the entire family as a unit dealing with the survivorship experience is important in facilitating communication among family members. Hasson-Ohayon et al. (2010) emphasizes that therapy for spouses and loved ones benefits the entire family. Talking about the cancer experience and sharing thoughts, ideas, and emotions can be a key component in coping well (Mallinger, Griggs, & Shields, 2006). Various studies involve women sharing their narratives of the changes in their lives that benefit them physically and emotionally. For example, Allen et al., (2009) conducted a study in which female participants gathered in focus groups and shared their narratives about how cancer enhanced their appreciation for living and willingness to move forward.

Women in the groups also shared that their desire to accept cancer as part of their lives also minimized their worry of potential recurrence.

Receiving emotional and practical support from spouses, children, parents, extended family members, and even friends is quite helpful for the cancer survivor (Thewes et al., 2004). Families have to learn how to relate to one another in different ways and acknowledge changes in each other. A number of research studies have shown that patients' feelings of being emotionally supported by loved ones are connected to lower levels of depressive symptoms and anxiety (Edwards & Clarke, 2004). At times, families have to make lifestyle adjustments and often have to communicate with one another about the absence of emotional support, facilitating some adjustment by simply talking openly about those experiences. Often, the loss of emotional support can leave the survivor and her loved ones discouraged, with hope depleted, which may develop into uncertainty and fear of recurrence. However, coping strategies and social support can provide an increase in hope that can potentially promote healthy survivorship (Stanton et al., 2002).

Shields and Rousseau (2004) conducted a focus group pilot study that generated common themes in working with survivors and their families. The therapeutic interventions in Shields and Rousseau's study showed positive changes in the patient and family's well-being, psychological functioning, and stress levels related to cancer. As a result, the researchers suggest having supportive programs for involved spouses, addressing open communication about their relationship to cancer, and identifying problems including life after treatment as key topics to discuss with families (Shields & Rousseau, 2004).

Managing Possible Recurrence

Moving toward a life of survivorship and the completion of treatment can leave a breast cancer survivor and her family unprepared for possible recurrence. For example, a woman has to adjust to her new role as a survivor, beginning a life that is different from before, without any preparation. When cancer patients transition to survivorship, they shift from a time of heightened awareness, worry, and multiple doctors' appointments—which come with a sense of personal assurance—to a time marked by taking care of themselves and monitoring their own health alone. Most recurrences in breast cancer are detected within five years of diagnosis, with a peak rate of recurrence during the second year following diagnosis (Burstein & Winer, 2000; Emens & Davidson, 2003). There is not a specific time at which breast cancer survivors can be considered definitively cured of their disease, because recurrences can occur more than 20 years after primary treatment. Studies show that more than a quarter of those recurrences are identified by survivors complaining about physical symptoms such as pain, shortness of breath, or even the discovery of another lump (Burstein & Winer, 2000; Emens & Davidson, 2003).

Each year in the United States, over one million individuals will be diagnosed with a recurrence of cancer, and more than half will, unfortunately, die from their illness (Anderson, Shapiro, & Farrar, 2005). Survivors and physicians acknowledge the importance of supportive relationships in adapting to and living with incidences of recurrence (Schapira, 2010). The preparation process for such a transition is not part of the initial oncology treatment. Naturally, emotional and physical challenges become common responses; but the impact of fear and uncertainty on the patient and loved ones' quality of life is not routinely addressed.

Feelings of vulnerability and possible recurrence become a shared experience for the survivor and her family members (Corbett, 2010; Rolland, 2005). Difficulty with simple tasks such as providing daily assistance with finances, insurance costs, and even work can arise with this shift in completed treatment. The survivor's previous history of treatment can affect her ability to obtain health insurance and even life insurance. In addition, financial challenges can arise because of limitations in working effectively due to the cancer diagnosis, which may necessitate limited work schedules (Hoffman, 2002). Families can suffer greatly because of these financial burdens, along with the anxiety related to the possibility of cancer returning again.

Some survivors have been able to work during and after treatment. However, if a survivor makes a life decision to retire, decrease full-time work hours, or even seek a different type of employment, she could potentially create more challenges if the cancer returns. Cancer survivors' managing of the potential of recurrence and the impact of quality of life changes provides opportunities for researchers to explore the need for survivors to maintain a healthy life after treatment.

Quality of Life

Good doctors know they can't make this go away, they can only hope
with me it will continue to move slowly, very slowly.

(S. Williams, personal communication, September 7, 2010).

Despite the prevalence of secondary cancer diagnoses, new medical advances allow patients to enjoy more years of survivorship with improved quality of life. The number of survivors has risen dramatically from three million in 1971 to an estimated 12 million in 2008; the largest group—accounting for 23% of total survivors—was breast cancer

survivors (Ries et.al, 2008). Quality of life refers to “complete social and psychological being: the individual’s performance of social roles, her mental acuity, her emotional state, her sense of well-being, and her relationships with others” (Levine, 1987, p. 4). It is important to note that quality of life changes occur over time due to the phase of illness, the patient’s age, and even her various life experiences (Bloom, Stewart, Johnston, & Banks, 1995).

Bloom et al. (1995) found that quality of life concerns differed for breast cancer patients who were 50 years old or younger at time of diagnosis when compared to older women. In essence, the hopes and expectations of the younger patients varied because of their different life decisions. For instance, different meanings were attributed to their expectations regarding their physical health and everyday functioning (Bloom et al., 1995). Studies conducted by Ganz et al. (1996) and Sarna (1993) reflect that older breast cancer survivors’ scores on quality of life assessments were better than the scores of younger survivors.

Overall, survivors’ quality of life is multi-dimensional, and may include adjustments to individual environment, education, family, friends, physical health, work, marriage, and close family relationships (Bloom et al., 1995). Therefore, each survivor may experience each domain differently, in relation to the different systems that may or may not play a role in her everyday living. Some people manage quite well in dealing with possible recurrence and maintaining a good quality of life (Rowland & Baker, 2005).

It is important to consider that resiliency with quality of life concerns varies for survivors and their loved ones, which can create challenges or positive adjustments toward maintaining a healthy lifestyle and physical health for the entire family system.

This can lead to an understanding about how surviving cancer and maintaining good health is central to developing a more collaborative approach to cancer treatment—both in offering psychosocial oncology research and presenting potential improvements in clinical practice within the medical family therapy field.

Medical Family Therapy

The fundamental principle of medical family therapy is “all human problems are biopsychosocial systems problems: there are no psychosocial problems without biological features and no biomedical problems without psychosocial features” (McDaniel, Doherty, & Hepworth, 1992, p. 26). Therefore, the foundation of medical family therapy involves the complex systems of biological, psychological, interpersonal, institutional, and community systems. A family therapist applies their knowledge of systems to assess and treat the patient from this approach. According to McDaniel et al. (1992), family therapists are trained within a discipline that emphasizes separating the mind from the body and focusing solely on psychosocial needs, leaving the medical issues to the medical doctors. Engel (2003) notes, “[physicians’] preoccupation with the body and with disease and the corresponding neglect of the patient as a person” (p. 7). Therapists’ concentration on only psychosocial issues leaves a gap in understanding the patient as a person, as this approach does not consider the other systems operating in relation to the person.

The role of medical family therapists is to offer a more collaborative approach to care that assists the patient and her loved ones during the course of the illness. The medical family therapy approach supports the patient-centered care mantra—incorporating the patient’s biological, emotional, social, and spiritual needs—to offer a

shared context when working with various systems including physicians, nurses, social workers, and other medical professionals. This approach is quite collaborative and utilizes a broadened view of information to construct a subjective view of families' experiences of cancer and survivorship. Having this view helps the family therapist coordinate a model of patient-centered care specific to each family and its concerns.

For instance, the family therapist utilize this framework and skill set to elicit patient and family stories about their functioning in biological, psychological, social, and spiritual systems that influence survivorship. The goal is to help the family recognize their sense of agency, personal control, communion, and interpersonal connection (McDaniel et al., 1992).

McDaniel, Doherty, and Hepworth (1997) identify common themes that emerged from their clinical practice with families and their illness narratives. The researchers' themes capture the challenges that families may face when dealing with cancer-related experiences. The themes found by McDaniel, et al. are as follows: denial versus acceptance; despair versus hope; secrecy versus sharing; guilt versus forgiveness; burden versus relief; isolation versus connection; passivity versus taking charge; fear versus courage; loss versus renewal; and senselessness versus meaning (1997). From a professional stance, I believe the 10 themes articulate the challenges quite well and highlight the experiences of families coping with the uncertainty of possible recurrence. Each theme seems to capture each person's unique response to the emotional challenges that arise due to cancer. It also creates an opening for families to have conversations and make meaning of those themes. In working with families dealing with illness, systemic interventions tend to allow space for healing feelings of loss, fear, and uncertainty.

Having family sessions that address the above themes can promote growth and change, but literature about what works with families is sparse. Understanding the cancer patient and loved ones' experience of the illness and survivorship from a biopsychosocial lens naturally allows the therapist to consider how intervening or providing support in each of those systems engenders hope and autonomy for the survivor and her family (Bischoff, Springer, Felix, & Hollist, 2011). However, I believe that the knowledge and skill set for therapeutic work as a medical family therapist can advance a step further in utilizing a social constructionist framework to capture social, cultural, and relational implications of survivorship.

A Postmodern Social Constructionist Lens on Cancer Survivorship

A review of the existing literature reveals that many of the writings on breast cancer patients and treatment are based upon the biopsychosocial model of care (Engel, 2003; Rolland, 2005; Thewes et al., 2004). Typically, the view within that model is of breast cancer as an organic disease. As a family therapist, the biopsychosocial approach is used to integrate the influence of the family and medicine from a systemic perspective (McDaniel et al., 1997). The therapist assists the patient and family members in understanding and accepting the illness by finding their strengths, identifying areas of concern, and offering them helpful resources (Linville, Hertlein, & Prouty, 2007). However, seeing breast cancer and survivorship only through a biopsychosocial lens limits the meaning, experience, context, and relational interactions of the survivor, loved ones, and cancer.

Gergen (1991) writes, "Under postmodern conditions, persons exist in the state of construction and reconstruction; it is a world where anything goes that can be negotiated"

(p. 7). Postmodernism draws upon the belief that there are multiple realities and there is no objective and identifiable truth. From this perspective, researchers and clinicians can collaborate in the conversations as patients and their loved ones construct, experience, and understand breast cancer and survivorship differently. The postmodern framework allows us to explore how patients and their family members construct, or even reconstruct, their experiences through interactions, language, and societal discourse (White, 2007).

Recent therapy outcome research shows that common factors, the therapeutic alliance, and the core Rogerian conditions of empathy and unconditional positive regard are quite helpful when working with patients and families facing illness (Kirschbaum & Jourdan, 2005; Wampold, 2007). Although tending to the internal process in psychotherapy is useful, it is not enough for some patients (Knight, 2007). Therapy within a social constructionist lens explores patients' and families' meanings around their encounters, behaviors, and emotions related to breast cancer, survivorship, the medical system, and how social and cultural aspects have influenced them. The therapist can listen and reflect families' language; learn through exchanges of stories and experiences; and create a safe, *comfortable* environment that allows their meanings of survivorship to unfold. My assumption and personal belief is that patients and their family members are experts in knowing what works best for them. My role as a postmodern, social constructionist researcher is that of a curious observer who is interested in learning about the unique stories of breast cancer patients and their families.

Psychosocial Support and Interventions

Limited information is known about survivors' support needs after treatment, how survivors manage challenges, and what resources have promoted healthy recovery and

management of survivors' health (Cappiello et al., 2007; Davis, Williams, Parle, Redman, & Turner, 2004; Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006; Stanton, 2006). The challenges and concerns for women and their families are not completely addressed, which allows room for research to provide therapeutic interventions for coping, stress management, and strategies for family members to enhance quality support for one another. A few studies have captured the experiences and needs of younger and older breast cancer survivors after treatment. Thewes et al. (2004) gathered qualitative data from 18 women who shared the importance of receiving emotional support from their spouses, children, parents, extended loved ones, and dear friends. For example, many of the women reported having a loved one there to offer physical support with daily activities and the emotional support of having a "shoulder to cry on and an ear to listen to you" (p. 183) as very useful. In addition to support from family and friends, women also spoke about the same type of support from their physicians and other medical professionals who were part of their continued care. Several participants noted that having that assurance allowed them to openly communicate their concerns and questions during follow-up appointments (Thewes et al., 2004).

In other research studies on survivors' needs, participants shared that after treatment, social support systems were present. Davis et al. (2004) and Lethborg and Kissane (2003) conducted studies in which the participants identified a need for resources and support during the transition to survivorship because they saw less social support from family, close friends, and health professionals. The findings clearly show that there is a continuous need for collaborative support in preparing women during, after, and

beyond cancer. While some studies report that support is present for survivors, others report a need to provide additional information and support for how to address the concerns of survivors and their family members.

In Thewes et al.'s (2004) study, support groups were reported by a few participants as being effective in moving forward after the completion of treatment. The women from the same study reported that speaking about being lonely and isolated promoted sharing among participants, and knowing that they were all going through similar experiences was useful. While some of the younger participants expressed that support was for "sick people," their perception changed because they were able to make a distinction between being a patient in the hospital and being a survivor who wanted to live a healthy life (Thewes et al., 2004).

In addition to the support group, some younger and older women who participated in the study requested individual counseling to obtain more resources and address their lack of family and friend support. The women's spouses were also interested in counseling, especially those of younger survivors with children. One participant stated, "I've got this beautiful little girl, it is not fair, how would she cope if she loses her mother?" (Thewes et al., 2004, p. 185). This heartfelt statement illustrates the continuous need for care of family members during this fragile time.

Several of the participants in Thewes et al.'s (2004) study spoke about communicating with their family about the course of treatment, but the researchers did not address how the loved ones provided care for themselves. Allen et al., (2009) identify the importance of providing emotional support to families who are managing stress and striving to be strong for the survivor. However, some of the family members studied by

the researchers were reportedly not emotionally available to support the breast cancer survivors' needs in a way that allowed them to get through difficult times and challenges (Allen et al., 2009).

Perhaps the most important finding that emerged from the few studies on survivors' needs was that some survivors, as well as their loved ones—who have been a part of their illness journey—have unmet needs. Even though psychological and support needs are being addressed through support groups or counseling sessions, more awareness and implementation of specific therapeutic interventions is key to bridging this gap in the course of illness and survivorship. Recommendations have been made by cancer survivorship policy organizers—despite the efforts of medical professionals and loved ones—to elicit as much psychosocial support and information as possible for survivors to improve their family functioning and emotional well-being.

Clinicians, specifically medical family therapists, have a role to play in recognizing and addressing the unmet psychosocial needs that continue beyond the end of treatment of breast cancer (Thewes et al., 2004). For instance, Oktay (2011) conducted a qualitative study to address the needs of women and their daughters. The narratives in Oktay's study reflect details about the survivors' lived experiences of breast cancer, and the researcher offers her own recommendations based on the impact on the entire family system. Based on her study, Oktay reports that family communication, preparation for treatment, and support are valuable for families during this period of time. Specifically, she emphasizes the importance of openly communicating about the emotional and physical aspects of challenges connected to the illness (Oktay, 2011).

Having mental health professionals facilitate the communication process and guide

conversations about the dangers of keeping secrets from the family can potentially be helpful for the patient and her loved ones. Family therapists can help with unmet needs of assisting families, discussing their fears, asking questions, and making meaning of uncertainty while moving forward together as a family (Oktay, 2011). We, as family therapists, can offer resources and normalize the challenges and emotions that arise from having a mother who is now a survivor of a life-threatening disease. In essence, family therapy can be an outlet for welcoming the changes, support, and other relational shifts families face during the survivorship process.

Why Examine the Couple's Experience of Cancer?

This study explores couples' experiences of illness within the context of professional and applied clinical research. While many researchers have conducted studies on cancer-diagnosed patients, research exploring the impact of cancer on the family and more specifically intimate partners is limited (Chalmers, Thompson, & Degner, 1996; Grunfeld et al., 2004; Shields & Rousseau, 2004). In addition, there is a limitation in understanding the unique experience of survivorship and the accompanying uncertainty that is common among couples from a social constructionist lens. The purpose of this study is to address this gap in the research.

It is important to conduct research about these experiences and the potential effects that breast cancer may have from a broadened systemic perspective. Cancer survivorship organizations have begun to address the physical, emotional, social, and spiritual aspects of living with and beyond cancer. Researchers have written about families' stories; however, the impact on the survivor and the intimate partner connected to her is limited. The objective of this body of work is to contribute to the professional

literature regarding the couple experience of cancer and survivorship, in hopes of aiding other patients, families, and medical professionals to listen for and attend to this unique illness experience.

Research on couples' experiences with breast cancer can provide researchers and medical family therapists with more direction for future study and application of knowledge when working within the context of diverse couples and families. This can be valuable in understanding specific cases and situations with patients and their experiences as a whole. As more and more couples and families deal with this common form of cancer, it is relevant to explore survivorship: physical changes, side effects of treatment, the emotions of patients and their loved ones, and the construction of couples' reality around breast cancer and survivorship.

Medical professionals can be challenged to attend to couples' experiences subjectively, given the normalcy within the traditional model of medical treatment and approaches to cancer care. Oncologists and other medical care professionals working with families and illness use an objective lens to develop a healthy survivorship plan for the patient. For instance, the course of cancer care aligns with specific models of comprehensive treatment plans after a patient has effectively completed treatment. Oncologists and their teams share follow-up treatments and supportive cancer services once patients have completed treatment.

In essence, cancer care providers often use both subjective and objective data to guide their decisions about care for survivors and those close to them. Naturally, a combination of practice would include the psychosocial concerns and needs of the family as a whole part of the health care experience.

Importance of Lived Experience Narratives

Professional literature on coping with survivorship addresses the psychosocial needs of breast cancer survivors but fails to discuss how these needs and beliefs also impact the family post-treatment (Allen et al., 2009; Tesauro et al., 2002; Thewes et al., 2004). The researchers who have studied coping during survivorship all identify a similar limitation in their research: their qualitative data provides rich insight into the experience of the individual patient but fails to include the experiences of the patient's loved ones, which could enhance readers' understanding of the whole cancer experience (Allen et al., 2009; Tesauro et al., 2002; Thewes et al., 2004).

Rolland (2005) refers to cancer as a family disease that affects not only the person with the diagnosis, but the person's family members as well. It is important to acknowledge that loved ones are at home providing caregiving needs and dealing with the possibility of cancer returning. Professionally, there is a need to offer assistance to families that are dealing with unmet needs that affect their functioning, emotions, and understanding of what it means to have cancer again. Their narratives will not only capture a snapshot of lived experiences and the phenomenon of the cancer experience, they will also offer a shared understanding to help families tend to challenges that could ultimately hinder their ability to flourish beyond the cancer.

Professional Research and Clinical Practice

How can family therapists assist families who are adjusting with life after treatment and grappling with the challenges of uncertainty and moving forward in life? Although this question is beyond a simple answer, my hope is to discuss ways in which research and clinical practice can attend to process and open the door for researchers to publish

more qualitative studies. I am interested in discovering ways in which families can establish their own strength, hope, and resilience. It is imperative to share multiple perspectives of families' experiences rather than just present a dominant discourse of family survivorship.

Much of the emerging research in medical family therapy that is focused on cancer care and the family primarily concentrates on interactions that are individually centered rather than family focused (Hodgson, McCammon, & Anderson, 2011). The goal of family therapists is to assist families as systemic units, including the patient and family members, rather than viewing them as separate systems. Researchers have identified that family therapy for cancer patients and their family members is a valuable resource that is highly underutilized (Sherman & Simonton, 2001). Sherman and Simonton's (2001) study, which reflects a systemic perspective, offers key tools that can be very helpful when working with families who have a loved one with cancer. For instance, family therapy tools can enhance communication, promote emotional support, facilitate meaning, improve adjustments to role changes, and address end of life issues (Hodgson et al., 2011).

Just as cancer patients seek information to actively choose their preferred medical treatments, there should be more readily available supported research on what happens next and what works after treatment is completed for cancer survivors. As part of preparation for treatment and life after treatment, patients and professionals should be able to educate themselves about this experience. As mentioned previously, there is not a set formula for the process of transitioning from *patient* to *survivor*, and there is a limited amount of research that offers subjective experiences of the family cancer experience.

Ellis and Bochner (1992) summarize the cancer experience by calling it “a social process for making lived experience understandable and meaningful” (p. 80).

The task is to gain a better understanding of multiple families’ lived experiences and how survivorship affects patients’ relationships with themselves and their intimate partners. As a therapist and researcher, I am influenced by postmodernism and social constructionism. I have chosen to delve into a research project that views breast cancer and survivorship beyond the traditional bio-medical lens, which tends to limit the social and psychological factors affecting the definition of breast cancer survivorship, the experience of it, and the changes that occur in patients’ relationships with themselves, loved ones, and the illness. Addressing how patients and families make meaning of those personal constructs within the uncertainty of recurrence and other challenges as they move toward identifying as breast cancer survivors can convey the necessary call for research and practice. It is my hope that we, family therapists, proceed in a way that advances the field of medical family therapy for the benefit of patients, survivors, families, therapists, and other medical care providers involved in this process.

Chapter III: METHODOLOGY

According to Patton (2002), a phenomenological study asks very important questions, including: “What is the meaning, structure, essence of the lived experience of this phenomenon for this person or group of people?” (p. 104). According to Marshall and Rossman (1999), there are “three major purposes for [qualitative] research: to explore, explain, or describe the phenomenon of interest” (p. 33). The authors assert that “many qualitative studies are descriptive and exploratory: They build rich descriptions of complex circumstances that are unexplored in the literature” (Marshall & Rossman, 1999, p. 33). There remains little available research that explores, explains, and describes the lived experience of survivors and families living with the uncertainty of a possible recurrence. To address this gap in the existing research, this phenomenological study focus on understanding the personal narrative of families surviving breast cancer. In this study, I aim to meet the standard of quality research, and my hope is

that those involved in this process, including those reading it, can take something away from experiencing our family’s shared experience of cancer. This approach opens up the study of lived experience(s), such that we may be able to touch people where they live and make our work linger in their minds. (Bochner, Ellis, & Tillman-Healy, 2000, p. 29)

To illustrate the research process for the present study, I first address how qualitative research fits within the context of a social constructionist framework and explain how a phenomenological approach fits into the larger tradition of qualitative research. Next, I address the origins of phenomenological inquiry. Lastly, I outline the procedures of the phenomenological methodology in completing this study, explaining

thoroughly how each step applies to an exploration of the lived experience of breast cancer survivors and their families.

Social Constructionist and Qualitative Research

To get a better understanding of the lived experience of those coping with breast cancer—the individuals surviving the illness and their loved ones—it is important to use a research approach that delves into the personal, shared experiences of families. To provide better insight into this type of experience, for the researcher and the reader, I used a qualitative approach that fits within the theoretical context of a social constructionist and postmodern framework. According to Boss, Dahl, and Kaplan (1996), family therapy researchers operate within seven philosophical assumptions when using phenomenological inquiry:

1. Knowledge is socially constructed and therefore tentative and incomplete.
2. Researchers are not separate from the phenomena they study.
3. Knowledge can be gained from art as well as science.
4. Bias is inherent in all research regardless of method used.
5. Common, everyday knowledge about family worlds is epistemologically important.
6. Language and meaning of everyday life are significant.
7. Objects, events, or situations can mean a variety of things to a variety of people in the family. (pp. 85-87)

The assumptions proposed by Boss et al. (1996) play a role in my research study and influence the questions I asked during interviews. My hope is to better understand the unique experiences of families. The study sought to move beyond dominant discourses,

which imply that all survivors and their families experience survivorship and uncertainty the same way. By utilizing a postmodern lens, I capture the unique experiences of survivorship and the uncertainty of possible recurrence.

Freedman and Combs (1996) state that our realities are constructed through social and relational interactions with one another. Through construction of realities, it is important to recognize language and how the interpretation of families' multiple perspectives shape their truth. Holstein and Gurbrium (1994) view language as a primary symbol in which meaning is both constructed and conveyed. Through this shift in language, survivors and families move away from conventional understandings to new meanings of their relationships, feelings, and beliefs (Freedman & Combs, 1996). Due to meaning making, a family dealing with the uncertainty of recurrence could possibly move toward finding language that represents an alternative storyline from what societal norms dictate.

This theoretical framework and qualitative inquiry explores how families might differ when dealing with similar challenges related to the uncertainty of breast cancer, which will merit more research attention than quantitative research studies have provided. Rossman and Rallis (1998) describe qualitative research as "a broad approach to the study of social phenomena; the approach is naturalistic, interpretative, and draws on multiple methods of inquiry" (p. 7).

Rossman and Rallis (1998) explain that in qualitative research, "the researcher is the means through which the study is conducted and the purpose is learning about some facet of the social world" (p. 6). Thus, qualitative inquiry engages in the essence of experience that is shared within the different lived experiences of families.

Phenomenology as a Method

Phenomenology is a unique method of qualitative research with a rich philosophical history. Patton (1990) defines phenomenological inquiry as “one that is focused on descriptions of what people experience and how it is that they experience what they experience (p. 71). Moustakas (1994) describes phenomenology as an everyday human experience that aims to “determine what an experience means for persons who have had the experience and are able to provide a comprehensive description of it” (p. 13). In other words, phenomenological inquiry seeks to understand a phenomenon within the context of the participant’s perspective (Moon, Dillon, & Sprenkle, 1990). In phenomenological research, the researcher does not begin with a hypothesis; instead, he or she “learns about the subject by experiencing it” (Sprenkle & Ball, 1996, p. 394). In hermetic phenomenology, there is a shift from description to interpretation among the context of the research findings (Finlay, 2011).

Creswell (1998) proposes the following process as a guideline of phenomenological inquiry:

1. The researcher needs to understand the philosophical perspectives behind the approach, especially the concept of studying how people experience a phenomenon.
2. The investigator writes research questions that explore the meaning of that experience for individuals and asks individuals to describe their everyday lived experience.

3. The investigator collects data from individuals who experienced the phenomenon under investigation. Typically, this information is collected through long interviews.
4. The phenomenological data analysis: the protocols are divided into statements or horizontalization, the units are transformed into clusters of meaning, tie the transformation together to make a general description of the experience, including textural description, what is experienced and structural description, i.e. how it is experienced.
5. The phenomenological report ends with the reader understanding better the essential, invariant structure of the experience. (p. 52)

These steps of inquiry invite the researcher and reader to gain a deeper understanding of the families' lived experience. In essence, the goal is to generate meaning of the shared experience within different lived experiences and perspectives of families living with uncertainty of possible recurrence.

Most importantly, as a researcher I want to evoke the lived experience of survivors and loved ones through explicit involvement of interpretation (Finlay, 2011). Finlay (2011) stated it best, "Different interpretation are tired out like dance steps. Eventually the researcher settles on particular meanings revealing possibilities that may excite, inform or point the way to future research" (p. 110).

Self-Reflection of the Researcher

In qualitative methodology, a researcher has to be aware that his or her experience can become part of the exchange through the interview and data analysis processes.

Thus, as a researcher, it is important to reflect upon my own assumptions, biases, and experiences as part of this research study.

It is important for me to be aware of my clinical and personal experiences with therapy and being a part of a family that is familiar with assisting others dealing with the cancer experience. These aspects of my professional and personal life bring about questions and curiosity that I want to contribute toward the research. My personal connection to the topic allowed me to explore and delve into conversational interviews with survivors and intimate partners that permitted me to connect with them on a deeper and more meaningful level. I wrote a journal entry after each interview so I could manage and reflect upon my own experiences.

Data Generation

Women in the cancer survivorship process and their family members were recruited from a university-based medical clinic located in the Midwest through the use of flyers, physician referrals, cancer survivorship support groups, and word of mouth. The sample population was generated through purposive and convenience sampling. The flyer consist of brief information about the study and invited women who were diagnosed with breast cancer, had been in remission for at least five years, and had attended therapy services throughout their process of diagnosis to participate in a research study investigating their unique illness experiences.

The participants in the study met the following criteria: (a) between 30-75 years of age; (b) diagnosed with breast cancer within five years of the beginning of the study and currently in remission; (c) an intimate partner that shared this survivorship experience; and (d) able to speak and read English. There were no limitations in cultural background, marital status, or religious preferences for the women and their significant others who participated in the study.

Data Collection

Upon recruitment, participants were contacted by phone to accept their invitation and receive details about the study. Thereafter, I scheduled the participants, along with their intimate partner, describe the types of questions that would ask in the interview; gave the length of time of the interview; explain the possibility that they would be contacted again to clarify any questions; and discuss their option to be interviewed either face-to-face interviews or via the Internet, using Skype. At the initial meeting, participants were given informed consent documents to review and sign. I provided the participants with a copy and filed the original in a locked file cabinet.

If participants elected to be interviewed via the Internet through Skype, I emailed the informed consent documents prior to their scheduled appointment. A copy of their informed consent document was scanned and emailed back to them. Internet interviewees were asked to review Skype's privacy policies, which are posted on the website, prior to their scheduled interview. The privacy policies include that Skype might collect personal information about users including (but not limited to) name, address, phone number, email address, age, gender, and IP address. Participants were informed that at any time during the study, they have the right to leave or refuse to participate without any penalty.

I explained the purpose of the study, answered any questions prior to moving forward with the actual interview, and stressed the importance of participants' confidentiality in the study. Following this process, I conducted open-ended interviews with the participating couples in a comfortable environment that was mutually agreed upon. The research questions that guided the interview were the following: How does a couple establish a clear vision of their lives when dealing with survivorship and the uncertainty of recurrence? How is the couple making meaning and coping with the changes breast cancer has caused in their lives? What role did psychotherapy and/or support groups play in their relationship and illness experience? Following these initial questions, I asked 10 meaning questions related their relationship to themselves and their couple relationship and how they cope with uncertainty of recurrence (See Appendix C). Each interview took approximately one to one and half hours to complete. It was important to offer a set range of time to give unity and consistency among each interview (Seidman, 2005).

All participants were given the option to contact the University of Nebraska Medical Center, Midtown Clinic or a referred family therapist if they need any additional therapeutic services as a result of the interview process and want to further explore any new discoveries about survivorship, uncertainty, and their relationships. The clinic serves the community using a patient-centered medical approach that is based upon offering health services, which focus on relationships, wellness, and prevention/treatment of the patient's health care. Participants would have to pay for their own therapy services, but the clinic works on a sliding fee scale. In addition, I asked permission to follow up with the participants, if necessary, to clarify any questions or responses that arise during the

interview process (Seidman, 2005). All interviews were digitally recorded. I had an additional recorder and batteries available if a malfunction occurred. Participants' names and personal information were discarded and replaced with pseudonyms.

Data Analysis

From a phenomenological lens, I analyzed the data to understand the meaning of the couples' experiences and how they manage the uncertainty of living with possible recurrence. The data analysis procedures consist of transcribing interviews, coding into categories, developing themes, and generating rich descriptions of the phenomena of the families' experiences. I was informed by Giorgi's (1985) key principles of phenomenological method of analysis:

1. Obtain a sense of the whole narrative.
2. Discrimination of meaning units within a psychological perspective with focus on the phenomenon being researched.
3. Transformation of the subject's everyday expressions into psychological language with emphasis on the phenomenon being investigated.
4. Synthesis of transformed meaning units into a consistent statement of the structure of learning. (pp.10-19)

I drew upon hermeneutic phenomenology more specifically interpretative phenomenology to abstract meaning of the survivor and loved ones' experience of survivorship through language and context. The goal in using this type of analysis was to understand the lived experience of the couples' life situations within their context (Finlay, 2011). Using the step-by-step data analysis guide from Smith, Flowers, and Larkin (2013), I listened to the digitally recorded interviews, in their entirety, several times.

After that step, I transcribed the participants' responses by listening to the digital recordings through headphones connected to my secured personal computer. The next step consisted of reading and re-reading the data until I was fully emerged in the data. Then, I began the process of initial note taking in the margins of the original data. Next, I developed themes from the data by focusing on large chunks of the transcripts and noting more overall themes. By searching for connections of themes, I began the process of moving from one interview to the next interview and began to bracket themes. Finally, I looked for patterns across the interviews and broaden the analysis by unfolding the interpretations of the data (Smith et al., 2013). In the course of analysis, I coded the interviews using the Track Changes feature in Microsoft Word to highlight any phrases, words, ideas, or patterns and assign labels that capture the essence of the experiences of survivors and their family members. This process created meaning units for each interview and eventually developed into an overall contextual understanding of their lived experience.

I transcribed after each completed interview to hone my transcription skills, gain a sense of the entire narrative, and to connect with questions, to help me become a better interviewer. After the completion of all interviews, I implemented member checking of the interviewees by emailing the transcribed interviews for them to verify accuracy. This shared member checking also contributes to the trustworthiness and credibility of the participant's narrative (Seidman, 2005). I followed up with them briefly over the phone or email. Participants were informed that they had one week to review their coded transcriptions and should not spend more than 30 minutes during this process. During the follow-up, I gave participants an opportunity to modify any information that was not

correct or that they felt was revealing too much. Charmaz (2006) points out to that in addition to data verification with the participant, the researcher is encouraged to engage in reflexive process of data examination and category construction. As researcher, I empathized and made sense of the data by drawing upon my own experiences of history, values, and beliefs (Finlay, 2011). It was important to reflect upon the experiences in awe and curiosity.

As the researcher, I held the responsibility for developing, interpreting, and creating the themes in the study. Although my findings provided verbatim examples of participant's experience and responses to the interview, the themes I created would to some degree be influenced by how I made meaning of survivors and loved one's experience (Finlay, 2011). The result of this process provides the reader with rich descriptions and meanings of the experiences of survivors and family members. It provides clinicians with more information about how families tend to manage uncertainty when dealing with the remission of cancer. By offering an understanding of participants' unique experiences of this process, I hope that practitioners can gain insight when working therapeutically with this population. I also offered a reflexive analysis of my emerged experiences as researcher. My goal was to be aware of the relationship and context of the participants and my influence on gathered data and overall findings.

Trustworthiness of Data

Meaning of life, differ from man to man —
 thus impossible to define in a general way
 (Frankl, 2006, p. 77).

In choosing a phenomenological approach to study the couple experience of breast cancer survivorship, I feel confident that I captured the essence of the participants' lived experience. Nevertheless, some readers might question the trustworthiness of the data gathered through this process of study. My goal was not to unfold the *truth* of how couples experience survivorship and manage the uncertainty of possible recurrence; rather, my hope was to present an account of participants' experiences that share their story of survivorship and explore the meaning that is generated for them about their sense of self, their relationships with one another, and the ways they cope with the uncertainty of recurrence.

According to Ellis (2000), "Communication about illness is not a static quality as presented in most research; instead participants and the quality and direction of their communication may change over time as illness worsens and relationships intensify or retreat" (p. 286). It is important to recognize that this research method allowed the participants space to share their experiences of making meaning from their own perspectives.

Quality Control and Ethics

I have taken into consideration that this might have been a sensitive topic for survivors and family members. Participants were given permission to voice any questions or concerns during any process of the research study. To insure the safety and

appropriateness of the research study, the Institutional Review Board (IRB) at Nova Southeastern University reviewed and approved the study. Confidentiality was guaranteed to all research participants; their names and any personal information were assigned pseudonyms. Data was stored on my home computer, which requires a password, and all other materials were locked in a file cabinet. Additionally, I back up the data on a hard drive that was stored in the locked file cabinet. Field notes, digital tape recordings, and all other identifying information will be destroyed at the end of this research project. After completion of transcription and approval of my committee, I sent the participants copies of their transcriptions by email. Finally, I sent follow-up emails to thank the participants again and verify that they received their personal transcriptions.

Consultations with my dissertation chair, Dr. Shelley Green, and my committee members offered me an opportunity to review my interview procedures and address the themes I identified during the data analysis process. Sharing my thoughts allowed me an opportunity to further reflect on this research project.

CHAPTER IV: DATA ANALYSIS

In this chapter, I illustrate the primary research findings of this study. The findings were developed using the analytical procedures described in the previous chapter. I begin the chapter by introducing five couples that participated in the study. After this introduction, I introduce each data category and present exemplars from my interviews with the breast cancer survivors and their intimate partners. A brief summary of my findings is included at the end of the chapter.

Interpretative phenomenological analysis (IPA) examines participants' significant life experiences as well as offers an interpretation of the data. This qualitative approach is dedicated to extracting the detailed experiences of participants, in order to capture what is happening for them. The researcher's interpretation of the data allows him or her to establish a connection to the participants' experiences and their accounts of these experiences. As Smith et al. (2013) describe, "IPA narrative represents a dialogue between participant and researcher and that is reflected in the interweaving of analytic commentary and raw extracts" (p. 110). In this chapter, I share details of the participants' experiences in ways that can lead to new understanding and meaning about their lives. Because IPA is a shared approach to research, I immersed myself in the participants' stories by asking questions to clarify and accurately reflect the lived experiences of breast cancer survivors and their intimate partners.

I began each interview by providing the couple with an explanation of the overarching questions and the goal of the research study—to explore how they make meaning and cope with the changes that occur in their relationship with themselves, their loved ones, and the illness itself. Their experiences were not limited to the diagnosis and

treatment, but included the social and psychological factors affecting their definition of breast cancer survivorship. The overarching research questions guiding the interview were the following: How does a couple establish a clear vision of their lives when dealing with survivorship and the uncertainty of recurrence? How is the couple making meaning and coping with the changes breast cancer has caused in their lives? What role did psychotherapy and/or support groups play in their relationship and illness experience?

In each interview, I used an open-ended style and asked 10 questions related to the participants' relationships and how they cope with the uncertainty of recurrence (Appendix C). The breast cancer survivors and their significant others were open and reflective in sharing their experiences with me. The detailed accounts about breast cancer survivorship offered in this story are intended to provide the reader with more understanding of the participants' journey, including the relational changes that occurred between each couple, as well as the strength and support they extended towards one another.

Description of Participants

I conducted my interviews with all of the five couples in the study via Skype. The interviews all lasted a minimum of one hour; the longest interview lasted an hour and a half. After completing the interviews, I sent each participant a copy of his or her transcribed interview for review. Four of the five interviewees reviewed the transcripts and provided minor corrections as well as additional comments.

Four of the interviewed couples were Caucasian-American, and the other couple was from the Republic of Panama. All of the participants' names have been changed to protect their personal identities.

Madison and Kasey. Madison and her husband reside in the New England area of the United States. Madison is a mother of three; she has two sons and one daughter. She and Kasey both look forward to major milestones as a family with their children entering high school and graduating from college in the near future. The couple celebrated their 12th wedding anniversary on the day of our interview. In addition to milestone, Madison was also celebrating that she only had to see her oncologist annually as opposed to every three months. Madison and Kasey are both active in the Relay for Life community. I was connected with Madison through a fellow Nova Southeastern University colleague. She shared with me that there is a history of breast cancer among her sisters.

Belinda and Kyle. Belinda and her husband Kyle reside in the Southeastern United States. The couple has celebrated 16 years of marriage and 17 years of being together. They both shared that it was “love at first sight.” In June 2008, Kyle had a major fall and suffered from head trauma, and Belinda was diagnosed with triple negative breast cancer. Belinda and Kyle are both family therapists and have a private practice together. As a couple, they value the perspective of “paying forward” by helping others in their community. Belinda was connected to me through an online breast cancer support group called Pink-Link. They did not disclose any family history of breast cancer in their interview.

Kelly and Greg. Kelly and her husband Greg reside in New England. The couple will celebrate their 50th wedding anniversary this fall. Kelly and Greg have two adult children: a son and daughter. Kelly has practiced as a marriage and family therapist for many years and is currently finishing her doctorate in family therapy. The couple value

their personal faith and open communication as key components in their relationship. They have been writing “love letters” to each other daily since February 1979, shortly after they attended a marriage encounter weekend. I was connected to Kelly through her doctoral program’s email list serve. Kelly has been cancer free for 14 years and reported no family history of breast cancer.

Lori and Alberto. Lori and her husband Alberto reside in the Republic of Panama in Central America. The couple has been married for 29 years. Lori and Alberto have three daughters. Their oldest daughters are twins. Lori is currently completing her doctorate degree in family therapy. The couple values the importance of spirituality and “living life to the fullest” as a family. Lori was connected to the research study through her doctoral program email list serve. She reported no family history of breast cancer and has been cancer free for five years.

Danielle and Sara. Danielle and her wife Sara reside in the Southeastern United States. The couple has been together for 24 years. They do not have any children but adore their dog and cat. Sara is currently completing her doctorate degree in family therapy and Danielle holds a doctorate degree in English. The couple values the importance of their families and close friends along with the “celebration in living.” I was connected with Danielle through Sara’s doctoral program email list serve. Danielle reported that both her mother and her grandmother were breast cancer survivors. Danielle shared that she initially had a lumpectomy, and later a double mastectomy, because of a recurrence scare a year after her initial treatment.

Presentation of Themes and Analysis

Table 1 lists emergent themes that I extracted from the data the IPA data analysis approach. According to Smith et al. (2013), “IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences” (p. 1). Using this type of analysis, I sought to examine what the experience was like for the couples while remaining sensitive and respectful of their accounts. In addition, I attempted to make sense of what the participants shared in their accounts. I used verbatim extracts from the participants to demonstrate the actual voices of the couples.

I developed the themes by synthesizing and mapping out connections and patterns from the actual transcripts and my initial notes. I identified key phrases, emotions, descriptions, explanations, and emotional responses. Then, I used Microsoft Word to document those descriptive comments and begin to reflect upon the “how” and “why” to gain a deeper understanding of the participants’ words and thoughts. Next, I proceeded into a more interpretive level of analysis by making conceptual comments and developing questions about the meaning of the data. Initially, I went through each transcript highlighting and commenting in the margins things I was curious about or stood out to me. Then, I would take a break from the transcripts and jot down any thoughts or questions in my research journal. I recall one day writing in my journal these two questions, “Who are they outside of being a couple who survived?” and “What do they value in life?” I found that being curious about those ideals moved my lens beyond what I was reading on the pages but probed me to think differently. I began to dig deeper in understanding their experiences on a broader level. I delve into this step by shifting my thought processes and that allowed me to see the data in a different way. Subsequently, I created a huge poster board

and mapped out any words or phrases that I felt represented their voices and experiences. In their description of this phase of data analysis, Smith et al. (2013) explain: “[the] purpose here is twofold: you need to give an account of your data, to communicate a sense of what the data are like, and you need to offer an interpretation of your data, to make a case for what they all mean” (p. 109). I typed each of them in bold font using Microsoft Word and printed each of them. Then, I positioned the data excerpts by separating, overlapping, or even removing any words or phrases from the visual board. The development of the emergent themes unfolded from the set of parts I had extracted from the interviews. This process allowed me to develop emergent themes. I found that by organizing the themes, I was able to be more creative and explore the patterns and connections on a higher level. The themes reflect not only the couples’ actual thoughts and words, but also my interpretation of their unique accounts. I have chosen segments of the couples’ interviews to focus on their descriptions of their experiences with cancer and survivorship.

Next, I created a table in Microsoft Word to organize themes and from there I formed the super-ordinate, emergent, and sub-themes. Super-ordinate themes were developed from the overarching categories of specific clusters and those clusters were abstracted into my emergent themes. From that process, I was able to go back and annotate each theme with page and line numbers from the actual transcripts. In addition to that, I created a new Microsoft Word file and I paste the actual transcript extracts. This entire process helped me closely examine data and verified that I captured the essence of the participants’ experience. As noted later in Table 1, the emergent themes are as follows:

1. Emotional Responses
2. Psychological Responses
3. Physical Responses/Complexity of Multiple Illness
4. Financial Responses
5. Support and Resources
6. Strength as Unit
7. Introspection/Reflection as a Couple

For the ease of reading the excerpts, I have edited “um’s” and “uh’s” because of some aspects of informal conversations. In some instances, phrasing or ellipses are significant in what the participants are expressing, so I did not alter those areas. The following text provides stories about the lives of the breast cancer survivors and their intimate partners with the intention of offering the reader a broader understanding of the participants’ lived experience. The results reflect the double hermeneutic of the IPA approach, in that the findings convey my interpretation of the participants’ interpretation of their shared experience (Smith et al., 2013).

From the transcribed couple interviews, I developed seven emergent themes that represent my interpretation of the couples’ highlighted verbatim quotes. From the emergent themes, I also identified sub-themes that deepen the interpretation of the data. Several of the themes intersect and overlap, as I did not make major adjustments to the themes in an effort to respect the integrity of the participants’ experiences. In reality, the couples’ experiences were so complex that it represents more both/and rather than either/or. Bateson describes this thought process as various levels of mind —unconscious, conscious, and external. It is not a matter of expressing your thoughts on one level

(p.470). By thinking on all three levels, one began to not focus on just the level of their experience of breast cancer on a conscious level, but step back and broaden their view on an unconscious and external level.

Table 1. Super-Ordinate, Emergent, and Sub-Themes		
Super-Ordinate Themes	Emergent Themes	Sub-Themes
Impact of Illness	Emotional Responses	Shock Worry Fear Comfort Strength Acceptance
	Psychological Responses	Anxiety Depression Fear of Actual Recurrence
	Physical Responses Complexity of Multiple Illness	Changes in Sexual Intimacy Severity of Cancer Diagnosis and Family History
	Financial Responses	Job Losses
Pressing Through: Living Beyond Breast Cancer	Support and Resources	Colleagues Friends Neighbors Oncology Medical Team Support Groups Psychotherapy Self-knowledge: Research
	Strength as Unit	Open Communication Spirituality and Faith Connection to True Emotions Relational Strengths
Making Meaning of Illness	Introspection/Reflection as a Couple	Celebration in Living Normalcy Future Milestones Value of Time Externalizing/Conceptualizing Cancer Acts of Kindness

The Shake: Impact of Illness and Survivorship

The diagnosis of breast cancer was a life-altering experience for the women and their intimate partners in this study. The stressors each couple endured resulted in different emotional, physical, and financial changes. Their lives were changed forever in an instant during a doctor's visit. The women and their intimate partners were not prepared for that moment, but each demonstrated resilience and strength by going through this process with their partners' support. The shared experience had an emotional impact on all of the couples, each couple moved towards survivorship in a unique way. Conventional principles of loss simply do not accurately describe the experiences of the couples in this study. Through the following exemplars, I highlight how the participants initially reacted, coped, and made meaning with various challenges. Each couple's experience was influenced by the dramatic changes brought on by the severity of the illness.

Initial Responses to Impact of Illness

The following excerpts present the participants' early reactions to the breast cancer diagnosis and how they conceptualized it as a couple. The couples varied in how they experienced the diagnosis, and their words capture their unique voices. These exemplars reflect a shift from talking about the diagnosis and treatment to talking about surviving and managing the uncertainty of possible recurrence.

Madison and Kasey.

Kasey: You know, for me . . . it was just the acceptance of the whole thing . . .

living with knowing that it's there and it can come back and not knowing what the future holds.

Madison: And for me . . . is wondering . . . how he thinks of me and how much it changed me . . . personally, physically, mentally . . . I think that's always a concern because I had reconstructive surgery done, so I'm not the same as I use to be.

Kelly and Greg.

Greg: So when [Kelly] came down with this diagnosis (long pause), as I remember it was an opportunity really to call on the Lord . . . and He responded immediately . . . I wouldn't say it increased our relationship in any way, but it certainly . . . it was a positive reinforcement.

Kelly: When I was diagnosed, I would always take care of myself. I went in for a normal mammogram, and I was absolutely blown away when the doctor kept saying, "We saw something . . . We saw something." I was very fortunate; if you have to have this . . . it was very tiny, but I think a piece of it that made it good for us or better for us. We were told right from the beginning that it wasn't life threatening . . . they referred to it as a small cancer.

Lori and Alberto.

Alberto: Well, I think when we got the diagnosis . . . it was, in my case . . . a very hard shock . . . you know, very shocking for me. I would say that the shock could be different to different people, to different couples. . . . In my case as a couple, as a person, I couldn't imagine really my life to continue without [Lori] as a couple, as a person.

Lori: I think that because of this shocking experience, I mean . . . even though I wasn't prepared for that . . . I could feel a little bump in my breast, so I knew that

something was happening. And even though when I went to the doctor . . . the doctor say that it was not . . . it was not malign. It was just a benign tumor, so I said, “Well even though its benign, I want to take it out”, but then I waited a year, and then it resulted that the diagnosis was wrong.

Physical Responses to Impact of Illness

While all the couples dealt with the emotional, psychological, and financial impact of breast cancer, a few of the couples managed other health conditions with their intimate partners. In the following excerpts, the couples describe how there was a complexity of multiple illnesses at the exact time of the breast cancer diagnosis. Each couple had to find a way to manage the impact of the breast cancer/survivorship along with additional health concerns.

The roles of caregiver were interconnected in a way that there were apparent role changes during the process. Sara admitted that there was a gift in her intimate partner, Danielle, having cancer, because it allowed Danielle to become more compassionate in her caregiving. Belinda was diagnosed within six months of taking care of her husband, Kyle, after he suffered a major fall that resulted in head trauma. The couple suffered from joint financial income loss because of their health conditions. Sara and Danielle and Belinda and Kyle shared different narratives about caring for one another in the midst of their multiple health concerns, but both couples found a way to cope with and make meaning out of overcoming these difficulties.

Danielle and Sara.

Sara: When we first met, she was a terrible caregiver. She couldn’t be there, like she had to walk out when I would get sick; it was really hard for her . . . Since

[Danielle] has survived cancer, I can absolutely trust she can emotionally be there mentally, be there physically, attentive; she is on top of the game . . . I'm not worried anymore; it's a pretty amazing thing.

Belinda and Kyle.

Belinda: It was very complex, because we had so much medical . . . medical hurdles to overcome that almost happened at once that my breast cancer survivorship is entwined really with [Kyle's] surviving a fall plus head trauma . . . I put my hand over my breast and I remember doing that and thinking to myself if this doesn't give me cancer nothing will, and six months later I was diagnosed. It's hard for me to isolate the two, because he was concerned about me and I was concerned about him and I wasn't concerned about myself . . . it was all mixed up.

Kyle: In December, she got diagnosed with breast cancer, so I stop worrying about my surviving . . . about the time she got her diagnosis they did a MRI on my brain and said that I had a stroke. I was very caught up in my own stuff, but when she got diagnosed with breast cancer I was afraid she would die, because it was a very . . . triple negative breast cancer. We both had to stop working and went through our entire 401K savings . . . finally disability kicked in. It was the dual impacts of losing our income and our careers was devastating, and then the fear that she was going to probably die within two or three years. Oh, so devastating! It was . . . what could I tell you, it was . . . we are so relieved now because it's past, and we made some adjustments, and things are much better.

Changes in Intimacy

In the following excerpts, the couples describe how the impact of cancer and other health conditions affected their sexual intimacy. The emotional and physical responses were not the only factors to address and make adjustment to during this process. It is quite common for couples to experience changes in their sex drive and comfort levels surrounding intimacy following a breast cancer diagnosis. There can be physical, emotional, and relational changes to manage as a result of the diagnosis. Danielle and Sara were able to openly communicate about intimacy, even though it was a difficult time for them. They were both open to re-discovering and creating a new way to connect again.

Danielle and Sara.

Danielle: I think the other difficult part of it is that I was pre-menopausal at the time I was diagnosed and then going through chemo accelerated that...so now I am in menopause. I wasn't ready to be in menopause yet and I'm still dealing with menopause. It's been two years now and I'm still dealing with menopause. I mean hot flashes hitting at any time of the day and night you know mood swings and such like that...I wasn't...I thought I had another five years until I will be in menopause and so it hitting that quickly in addition to everything else was something I was not ready for.

Sara: In regards to the menopause...I was already in menopause naturally and so when she went into menopause that was like the start of impacting our sexual intimacy. We were accustomed to my body's response because I am also a kidney transplant patient and so that impacts our sexual activity...it was like okay now we have to figure out another way to incorporate all this. I think for

her to be in menopause; it was still part of her natural piece that helped us. It's made the difference; you know that we now finding another let's figure out how to get across this one...that's one thing.

Emotional Responses to Impact of Illness

In addition to introducing physical challenges and changes in intimacy, the diagnosis of breast cancer also brought along emotional stressors for the couples in this study. The following excerpts highlight the couples' emotional responses of shock, anxiety, depression, worry, fear, comfort, strength, and acceptance.

Belinda and Kyle.

Kyle: We are both therapists and we have processed everything together. Some people pull apart very easily in times of stress; we pull together during time of stress, so we both would be resources for each other. I think if anything, it strengthens us as a couple. It scared the hell out of us, but it strengthens us as couple. We had to face the dying scenario and what we were going to do. . . I guess the way we made it through was to rely on each other and to be there for each other. We didn't take our anxiety or anger out on each other.

Belinda: I was trying to survive and the person [her husband] that I counted on the most was gone. Yet, it is really a very central aspect of my breast cancer now and that both together . . . my breast cancer is triple . . . usually it's prevalent among African American pre-menopausal women. I was never concerned about breast cancer. I didn't have much in my family, it was not something I was afraid of, so I was stunned. I mean literally . . . I can't describe the shock to find out. I have breast cancer, and I had done my own research to find out that it was triple

negative, which if it's gonna kill you it usually comes back and kills you in the first three years . . . so that was a lot to get your mind around and at the same time that your husband has that complex of illness.

Madison and Kasey.

Madison: I think sometimes it bugs him because I'm always thinking or worried that it's going to come back. Like I had my five year last year, and his comment was, "Now you can think of it less." But for me, I don't I think I'm ever going to stop thinking about it. I just try to not talk about it a lot because it really bugs him, so that's a little bit of our challenge together.

Kasey: There's no way that I can forget about it, but I definitely try not to think about it . . . until there is a recurrence. I want to, in some ways, pretend it never happened. Because we're at a point now where we can be comfortable in knowing that things are good and you don't want to always, you know, figure out what can possibly happen in the future.

Kelly and Greg.

Kelly: Probably . . . how long, maybe the 1st year or 2nd, I couldn't have a cold, because if I had a cold I was just convinced that the cancer came back and it was everywhere. And you know, you can't have a pain. It's the process of oh my god because I have to say that just hearing that word the first time was difficult to go through . . . that thought that it would recur. It's just, you tell yourself, I could never go through that again, but I guess you do what you have to do. Every time I'm going to any of these [doctor appointments] I get upset; it depends on where I am that day, but especially if it's a test. I'm crazy . . . I don't even know my

name, and they make you fill out all these things and they ask you. One time, I couldn't remember my name I was so nervous . . . you don't get the results right away, so you're waiting to get those results. So those are kind of, like, the side affects for me, but I don't dwell on it.

Lori and Alberto.

Lori: I can't exactly explain how, but even in the moment I said, "Okay I will do what I have to do," and "I take what I have to take". . . and that's it, but the difference was I'm saying or trying to say. If I'm going to die and in peace, but I don't want to be thinking that I'm going to die tomorrow or the next day after; I mean, I don't like that idea. I just want to say alright; I'm going to see my grandchildren and I'm going to live and do whatever I want to do. That's a fact. I can't say I'm not going to die, but I'm not thinking everyday, I'm going to die in a car accident, I mean, or something or whatever. It's something that's the way I, like, I really like to think I'm going to be around if not that's plan B.

Danielle and Sara.

Danielle: I put all my energy into surviving treatment, going through chemo going through radiation, and then I was done. It was like okay I'm done and all of a sudden . . . I was severely depressed to the point of I kept thinking of ways to kill myself. It was . . . I wasn't actively suicidal, but I had suicidal ideation, I guess you would say. I had to get on an antidepressant and see a therapist . . . that was really difficult.

Sara: Yes, the biggest one is the fear. It just seems to be gone. My mother says it to me probably every time we talk . . . that's pretty important, because we are very

emotionally oriented to the world, very sensitive to people's emotions. The fear is just not there anymore and the anger.

Overall, the emotional responses described by the five couples were unique, but there was a common thread of heightened awareness. The emotional responses even differed between each of the couples. For instance, the participants attributed different meanings to their vulnerabilities regarding the phase of ending treatment and the possibility of recurrence. Although the couples initially reported shock and fear in response to the diagnosis, they described definitive shifts in their experiences that included less worry and uneasiness towards survivorship. Some of the women were still a bit anxious around certain tests or even after their five-year milestone. For example, one couple shared how the wife would become anxious prior to her scheduled follow-up appointments but was more at ease once they processed the common concerns.

Another couple shared that she had more frequent thoughts about it recurring, but her husband tried not to think about it much. Although their thought processes and emotions around recurrence were different, they were able to come together and respectfully validate each other's emotions. It is important to recognize the resilience of the breast cancer survivors and their intimate partners during this process of living beyond cancer. Each couple juggled several stressors during this season in their lives but was able to find a way to cope and move forward to survive the illness together as a unit.

Pressing Through and Living Beyond Cancer: Support and Resources

Each couple shared the importance of their marital relationship, as well as their network of family and friends, as being a key component in making a good transition towards survivorship. In addition, they explained that open communication was also

important in surviving and moving towards a healthy life beyond cancer. The couples shared that having an outlet to talk about their shared experience of cancer and express their emotions and thoughts benefited them greatly.

The following excerpts highlight the couples' support systems, which included family, friends, medical professionals, psychotherapy, and self-driven research assisted in moving forward with a healthy quality of life.

Family and Friend Support

For the participants in this study, family and friends were quite helpful in offering emotional, physical, and at times even financial support. The couples expressed how the additional support allowed them room to cope well and handle any stressors. It was clear among all the couples in the study that having spousal support was a blessing, but each expressed that additional support from extended family, friends, neighbors, and co-workers was just as important. The following excerpts convey how those support systems were valuable for the couples.

Danielle and Sara.

Danielle: So I think it helped a lot . . . seeing what she [mother's a breast cancer survivor] gone through . . . I had lots of support that reason. . . . I had her support . . . I had support of [Sara's] family . . . I had [Sara], I had great support of my work. I could take off the time I needed and still get full pay full benefits . . . the whole bit. All my co-workers and the managers were very supportive. There were really good support groups around here that I joined were very helpful . . . And I think what was also helpful the fact that [Sara] and I were only have to be responsible to each other. We don't have children. I know that can

play a big factor in a family or partnership . . . in they [other couples] have children, and they have to deal with having cancer and having to take care of kids etc. It's just me and [Sara] . . . our cat and dog.

Sara: So my support came in taking care of her . . . came through my mom who lives about two and half hours away . . . probably my role model from being the caretaker from hell. . . . It's a loving term. [Laughter] I would say she [Sara's mother] was probably first . . . right underneath that would be our best friends. We have happened to call them our husbands . . . it's a gay couple that we are matched perfectly with . . . they would call me, I mean, I don't know, maybe every two three days and say, "Okay what do we need to do now?"

Madison and Kasey.

Kasey: We have a lot of support friends . . . family.

Madison: You know . . . I have a close friend whom I'm very close with her. My best friend. She is actually wonderful. . . . I had another girlfriend that you know, hear me cry. . . . I had two really close knit friends that were there that I could come to.

Kelly and Greg.

Kelly: We have wonderful children, and our daughter is a social worker and she's a medical social worker and she had been working for CancerCare at the time in New York City . . . so she knew all the doctors who, the language, and she came with us and she listened with her professional ear. Because you know your head goes under water when you start discussing, no matter how much your training . . . all they have to say is that you got cancer and you don't hear anything after that.

So she was wonderful . . . so kind of, she fought the insurance for us. And also we have a son that's married. He doesn't live close to us . . . he lives in the Buffalo area of New York State, which is way upstate, which is about 500 miles away. He is also very attentive, and he flew down here. He kept coming all the time. He was here the day of surgery. So I guess our family. [Greg's] sisters came. They don't live close, but they came to visit me. . . . Just family and friends were very supportive. We just felt very blessed that we had each other.

Belinda and Kyle.

Kyle: I value my partnership very, very much. If anything I value it just about everything. . . . So being willing, for both us to be willing to just go through whatever we had to go through and hang in there . . . and do it together . . . it was what we needed to do, and we were able to do it. . . . I thank God.

Psychotherapy and Support Groups

When stressors continue, couples often seek therapy to find solutions to manage their challenges. In the following excerpts, both couples described how psychotherapy and support groups were options to manage the changes that occurred during this process. Only two of the five couples attended therapy sessions together. Danielle and Lori attended individual therapy sessions to have additional support. The women in the study expressed that they were connected to a support group at some point. On the other hand, their intimate partners were not involved in any support groups. A few of the couples did attend support meetings together as a couple on some occasions.

Belinda and Kyle.

Belinda: Well, we had a couple of visits [psychotherapy], not meaning to sound egotistical, but both of us are quite mature, and we had a hard time finding anyone with enough clinical skills to help us much . . . really, and pretty much did it, well, on our own. It was resources [local community] that we did not know we had and you know it that's why I call it the "net," literally. It was as if a net appeared.

Now in that, in the midst of it all, Kimberley, you know, existentially I wonder about that net . . . why it doesn't appear for everyone. It's strange. . . . It really is a miraculous thing. I don't know why I was so blessed; I do not know.

I didn't go to a breast cancer support group for years, and a doctor friend of mine really wanted me to go because they did not have anyone to facilitate. It was just . . . it wasn't going anywhere, and the women weren't getting the support. So I went and I didn't find it very comforting, because so many of the women who had cancer two three times . . . horrible things that touched me. I have the skills to help there and to facilitate there, so I continued to go and I will continue to go, but I don't get support there. I get my heart further broken, and my heart has taken a lot of beatings. . . . I'm still happy that I have something to offer, so I'll keep going.

Lori and Alberto.

Lori: I went to psychotherapy myself. I mean, I came back to my psychologist and I said, "Well this is happening. I really want your support." I did it on my own. . . . I went individually at the beginning, then we went as a couple; but just a few sessions, not much. And not precisely when we went as a couple it was not

more the issue of the breast cancer . . . there were some other issues, other things. But when I was just now diagnosed, I just went right away. I suppose . . . I went to handle this in a better way, so I went to psychotherapy.

Danielle and Sara.

Danielle: Well actually . . . I still go to my support group near where we live called Bosom Buddies. It was the support group my mother attended. So I decided to attend that one because my mother went to it even though it's at a different facility. My best resources right now are the survivors when I go to my support group. We met once a month. . . . Its about the survivors. We help each other. . . . It's really, in my experience, nothing else. . . . I do fundraising for the American Cancer Society. I ride a motorcycle with a group of women; a couple of them are survivors. I meet other survivors in everyday life. I always wear my pink survivor bracelet, and other survivors see it. . . . We talk and we share stories, and that's the support I get . . . besides my loving wife. But not from any official or medical, it's just what survivors we do. . . . It's survivors together . . . we support one another.

Kelly and Greg.

Kelly: I went to a support group, but it turned out to be more of me helping them than them helping me. I went locally. We have a local university, which gives the doctor in psychology, not marriage and family. . . . They have a very strong breast cancer support group. . . . They have a major support group, which is absolutely wonderful. After I was diagnosed, I thought maybe it would be helpful if I joined

this group . . . and I joined the group. And the woman, unfortunately . . . the facilitator . . . she sort of leaned on me to be like more a helper than a patient.

The participants differed in how psychosocial support and other resources promoted healthy living for them. However, their family and friends were definitely noted as being beneficial resources for them. Some chose psychotherapy and support groups and found it to be useful. A few of the women shared that they did not attend such groups, because they became facilitators more than attendees receiving support. The women and their significant others also spoke about the importance of support from their physicians and other medical team professionals. The participants' excerpts note how much openly communicating their concerns and developing trust with members of their medical team was vital in their continued care.

Several significant others were active in the process to ensure that their partners' physicians would build a relationship that offered respect, understanding, and connection with their desired plan of care. I had an extended conversation with a few of the significant others about their doctor consultation visits. They shared that they came prepared with various questions as part of their own interview process to select the best oncologist to care for their spouses. The doctor/patient relationship offered the couples not only a level of confidence, but also support in knowing that they would get through this process.

Oncologist and Medical Team Support

The following excerpts illustrate the nature of the couples' conversations with their medical teams and show how they developed a strong rapport that helped them to move forward successfully regarding the survivors' healthcare.

Madison and Kasey.

Madison: We basically told him we were interviewing him. . . . He wasn't going to be the doctor if I didn't like him. We went in and we had our consultation. . . . You need to make sure the questions you're asking are getting the answers, especially from your oncologist . . . cause you're going to have a lot of questions. You're going to have a lot of concerns, and if they aren't willing or able to handle or answer you. To me, I would have never felt comfortable . . . you know, if my oncologist didn't have that answer he [oncologist] goes and "I will get back to you." He called me one time at nine o'clock at night with one of our answers to one of our questions. He sat there and did research, and that's the thing . . . you have to feel comfortable and willing to ask your doctor questions and get the answers that you feel that's comfortable for you.

Kasey: For me its about connection you weren't just a number. The surgeon himself was fantastic...for me one of the best surgeons I had ever met. Personally you know he was honest... when he gave us results the first time he was emotional about it...he cared.

Kelly and Greg.

Kelly: I found a doctor who . . . a female doctor. . . . She was on the cutting edge and very bright, and she had dedicated her whole life—a great person—to helping women with breast cancer.

Danielle and Sara.

Sara: He [radiation oncologist] would do this behavior where he tried to be supportive because his wife had survived breast cancer, and he would act in this

way that he knew everything and would talk through everything for me. It was the most irritating experience. . . . But for her, she was soaking in, so to speak, every ounce of encouragement she could get from anybody. Not to say it was a negative thing; I think it was part of the survivorship. . . . I think she needed to do but that was one of like the support from Tulane directly from the physician. I think the other was the oncologist put up with me. (Laughter) And because I had so much experience talking with doctors asking questions became really comfortable. . . . But first time maybe, or not long after, we met with the oncologist was to start the chemotherapy process. I had a list of questions. I was challenging her responses to make sure . . . I understood what to expect, because I had never been through (cough) anyone with cancer.

Lori and Alberto.

Alberto: He [second oncologist] explained in such a way . . . after that interview we were . . . I was very calm. I have to say he didn't say the same thing that the other doctor did . . . that was very important. I think that the other doctor . . . I don't want to talk about him badly, but I think he was not too experienced, and he probably was not the correct one to explain to us the problem. When we got in with the second doctor, I felt we knew that we were going to fight against the cancer. We knew that we want to make a surgery. . . . We knew that we had to have chemotherapy, but in a completely . . . I think that after that interview we scheduled the surgery, and probably a week or two weeks after that experience. In my case, I feel very confident about how . . . with everything going to be as I told

you. My thinking, and I use this thinking very often when I explain to other people . . . we couldn't ask for nothing more.

Lori: I just I remember once I just came from the doctor and the doctor said, "Everything was alright." And I said, "If the doctor said everything is alright, why am I worried?" I said, "If something is going to happen . . . if something is going to appear, I just can't do anything at this moment." So I have many things that I have to do . . . because I'm doing many things . . . in the moment in my life. So I don't think I have to worry about that. . . . It goes very quickly.

Belinda and Kyle.

Kyle: When the oncologist wanted to use a very heavy duty and intensive chemotherapy, I warned him that I knew B.'s immune system would not take an intense treatment. And, of course, I was . . . it was my opinion. I was not considered very much. Well, sure enough, it turned out right after her first treatment. She was hospitalized with heart failure, which could have killed her. Afterwards, the doctor apologized to me: "You were right . . . I was wrong." I thought he had made a good response—professional acceptance—but sometimes doctors really need to really listen to their patients and their spouses. They know a lot about each other, and if you can integrate what the spouses and the patients know and are willing to tell the doctor, it sometimes helps the doctor in choosing more appropriate treatment. They really need to respect the decision that the couples make about treatment.

In addition to the positive patient/doctor relationship, a few of the couples utilized their own knowledge base by conducting additional research on breast cancer and

treatment. Having confidence and expertise of their oncologists was vital for the couples, but taking personal time to complete self-guided research was another useful resource for several couples.

The couples continually stressed the importance of being well informed and prepared for their doctors' visits. They shared that they would often present their doctors with concerns, ask questions, or share new insights that they discovered during their own research. Several of the couples found that their physicians began to recommend what they found through their personal research to other patients.

Self-knowledge Through Guided Research

The following exemplars emphasize how the couples' information gathering efforts aligned with their physicians' recommendations.

Kelly and Greg.

Kelly: I would do my treadmill, and I would get the whole body going. And if I wasn't going to work, I would take a nap. At that time, my daughter would have worked for CancerCare for six or seven years. I had resources at CancerCare. . . . I don't know anyone anymore, because she's no longer there, but I would listen to their conferences. . . . They would have teleconferences, Skype conferences like this. Now it's funny . . . now they're recommending people should go for therapy, and now they're saying to exercise everyday. They didn't tell me to do that. And you should take a nap, and you should . . . So I think maybe 14 years . . . maybe we are in a different place . . . maybe that could be a piece of it. . . . All through my life, I have been in school. My whole life. Any time I don't know, I would go research it myself . . . whether it was before . . . there was internet. We were at the

public library, or when my kids were little, or my mom or dad had something. I would be researching all over the place and get as much knowledge as I could. I guess I always felt that through life. . . . You rely on the Lord and rely on yourself. I always say that medical care delivery system is so tough, and if you don't have someone to advocate for you . . . you're in deep whatever.

Belinda and Kyle.

Belinda: Well . . . oh good heavens, when I came back my surgeon told us that I had a 98 % chance of survival. Thank God it was stage one. . . . Well I asked for the path report, because that's the kind of person I am. I research everything. . . . [Kyle] and I started looking up and deduced that I had triple negative breast cancer, and that my chance of survival was at like 69-70% percent, and we had a three-week period of Christmas . . . because we saw an oncologist. Had we not researched it, I would have not known. . . . I would have walked into the oncologist office and thought it was just a one-time visit. So it was in that three weeks . . . Talking about pulling together, it was like two monkeys trying to read Swahili. I mean we were just digging for every bit of information we could get. We literally researched almost every minute we were awake. . . . So by the time we got to the oncologist we knew . . . what we were dealing with, and that's just talking about . . . you hear, of course, you can't separate the physical from the psychological. The psychological fear . . . in feeling like your caretaker was clueless was a pretty horrifying feeling. In terms of us looking back, since you asked, I imagine that . . . three weeks cemented something . . . cemented a lot for our survival.

The participants' previous excerpts support how communication and trust in their oncologists and other medical support team members helped them strive towards a healthy and continuous path in survivorship. Likewise, the couples' resilience and trust in one another was demonstrated by overcoming the obstacles of illness together. They found ways to make adjustments as a couple to enhance their relationships as well as their families. The couples' determination to seek answers for themselves was also vital in presenting their questions and thoughts in finding the best treatment plan.

The following excerpts highlight the couples' shifts in perspective after the diagnosis, treatment, and breast cancer survivorship. The couples note how they were able to move beyond the illness and continue to flourish in daily life by tapping into their strengths. Spirituality and faith, connection to true emotions, open communication, and relational strengths within the couple relationship were a few sub-themes in the couples' reflections on how they shifted their outlook.

Open Communication and Emotional Connection

The couples in the study reported that they had been in long-term relationships and attributed their lasting commitment to one another as being a great strength. Throughout the interviews, the participants were open and honest about the ups and downs of their relationships. It was quite apparent that the illness journey affected them, but they were able to express their thoughts and emotions. This ability not only guided them through the illness journey, but also was a common factor in each couple relationship. The following excerpts display how the couples were able to communicate openly with one another.

Madison and Kasey.

Madison: To be honest, we can talk together. . . . We've known each other since we were infants. I think the key is communication; if you don't have communication, you . . . like if I have a bad day and I've just. . . . He would come home, see what was the issue today, and what we were feeling . . . you might be thinking, you know. So it's that kind of communication . . . if a couple goes through it . . . really need that reassurance.

Kelly and Greg.

Greg: I'll explain something to you. Thirty-five years ago when made this weekend [marriage retreat] we learned a technique in communication. We refer to as writing a love letter, and in fact we just celebrated our 35th weekend year anniversary, and we had at the point written 12,755 love letters. We have written every single day since that weekend. . . . Yes, and it's through these love letters that we have the opportunity . . . really to express our feelings, and then we discuss them. So this is how we deal with . . . this pressure, whether it's a test coming up or whatever. We have an opportunity to sit down, write it down, and discuss it.

Kelly: It is when we sit down every day and we have a topic and it doesn't even matter what the topic is . . . it's snowing again. We had some snow here, but it just brings out . . . it's true, it brings out where you are at that moment, and so we just talk about our feelings. . . . So I can get very crazy when I have to go get these tests. I can just write it all out and get it out, and then he listens. And he

doesn't always agree, but it's kind of like . . . it's good though, because then you get it out.

Danielle and Sara.

Danielle: So while in some parts of my life I find that I am . . . you know, I've found a new strength in exercise and being healthy. . . . I found emotionally, but I find that I'm a bit steadier now . . . if that makes any sense . . . more calm.

Sara: It's just gone . . . like we don't have this protective shield around her anymore. I was the only one who could get through . . . like it's just not there. It's so obvious that her emotional wellbeing is much more stable now. Because she don't have to disappear endlessly into books and TV like she did when she was really scared. . . . She interacts more.

While emotionally connecting and communicating effectively were key in the continuum of moving forward, the couples found affirmation in what they already did well together. The following excerpts demonstrate how their strength remained dominant even in pressing through their journey of illness.

Support of Relational Strengths

Even though the couples expressed that their emotional connections and communication were strong, they noted other relational improvements as part of their cancer experience. The couples openly discussed how they were more attentive, loving, and caring towards their partners. It seems those strengths were present prior to the illness but were displayed more, or even shared more frequently, towards one another. The following excerpts demonstrate how the care and love in the couples' relationships were highlighted during this time.

Lori and Alberto.

Lori: Our relationship changed a lot at the moment, because [Alberto] was so nervous and, in fact, he changed the way he was treating me. I mean, he became so much loving, so much . . . caring, and we had a normal relationship before. It was like a normal life. We had good things and problems and everything, but we were okay. But at that moment the relationship became like, “Oh my goodness,” like you are the most important thing for me, and in a way I felt, like, overwhelmed.

Kelly and Greg.

Greg: Well I think it certainly confirmed what we believe ourselves to be. We knew we were very strong; I think it just reinforced the strength that we already had. It just made us, well, instead of . . . it's like . . . learning a theory before the incident happened. We theorized that we were very close. . . . We didn't have any problems, things were going along very smoothly. Then after this, we were able to demonstrate our strength, so it confirmed what we already built and developed to me. (Laughter)

Belinda and Kyle.

Kyle: We've been lucky. . . . We've been very fortunate too. At first we thought for sure we're going to need marital therapy to get through this, and we did talk to a couple of therapists, but we've been able to manage surprisingly well pretty much on our own. It's been . . . it's been a very gratifying . . . we didn't know at first that it was going work out this well. . . . It worked out, and I think it's one of those things. When I was . . . I find myself being very irritable and very angry and

very argumentative. It was knowing and . . . I was willing to do whatever. My psychiatrist told me what to do in terms of medication because I realized . . . it wasn't me and it was going to destroy my marriage. I talk about making one pliable . . . I don't want my marriage to be destroyed.

The well-known vow “for better or worse” was definitely tested for the couples in the study. The boldness of their togetherness was stretched, but their love and care for one another was brilliantly affirmed. Several couples expressed that they were surprised by how strong they were as a unit through the adversity. The shared experience of managing the adjustments and challenges due to the illness did not dampen their relationships, but reinforced them. Certainly, the couples acknowledged that it was not always a smooth ride, but they were able to get past the speed bumps together. The basics of strong communication, emotional support, and openness to change were all utilized during various phases, but there was strong influence from a higher being that strengthened some of the couples even more.

Spirituality and Faith

It was essential for the women and their intimate partners to talk openly, receive emotional support, identify, and make some relational adjustments. Some couples used letter writing or a daily check-in, which made a difference in how they were able to adjust and move forward together. Additionally, spirituality and faith restored their hope in overcoming breast cancer and living well.

For some of the couples, spirituality and faith were present prior to the diagnosis of breast cancer and evolved as a result of the illness. Several couples expressed that it had always been present in their lives but became more influential for them individually

and together. They also expressed how their spiritual connection strengthened their relationships and offered them the power to keep going. The following excerpts convey the importance of the couples' spiritual connection to a higher being and illustrate how their faith increased given all the life altering changes.

Kelly and Greg.

Kelly: I think we always had God, but He was probably asleep or He was in the closet somewhere, and this weekend [marriage encounter] was very spiritual. It was so much . . . you don't have to be religious, you don't have to go to church, but this was really the explanation, really, in order to keep our marriage going. You needed the triangle, and not Murray Bowen's triangle, but the triangle of God and the couple. . . . And so it strengthen that for us.

Belinda and Kyle.

Belinda: This was a shocking transition for me in every aspect in being and to have people . . . I didn't know come out of nowhere and reach out to me. It was astounding. . . . This was another insight I got: The people that helped the most were not the people who had money, it was the people who didn't have money. This lady cared for me because, as she thought, I had been good to her son. All I did was do what I do, being me, but she called me and said, "I have a diamond ring I want to donate for your raffle." I mean, she lives in a trailer and was losing her business. That's spiritual. I mean, I guess my spiritual life is summed up in to "much is given much is expected." So we have always . . . [Kyle] and I have always been the kind of people . . . that did what we can for somebody. I'm

certainly not Mother Theresa. I don't go out volunteering and bringing the homeless and all . . . It's amazing really. . . . It's quite a story on all levels.

Lori and Alberto.

Alberto: I felt very, very confident about how were going to do with everything. I think [Lori] because of her discipline and preparation and the kind of person that she is, and the other thing I think is faith. Her faith is so strong I didn't feel we needed additional support.

Lori: Spiritual experience or something, I think for me it has been a great support . . . a very intimate time where you are also in touch with this . . . superior entity in who you believe, and it also very special experience. And more than that it is a very . . . for me it was like a enriching, empowering, you know, like I felt like I could live a very intimate way with my own situation. It was for me . . . it was a good thing.

Several couples emphasized the importance that something larger than them provided a source of comfort and peace in the midst of their life-changing experience. The process of reconnecting with faith and a higher being was not only an additional resource of support, but also something that empowered them in an exceptional way, individually and collectively. The spiritual path led the survivors and their intimate partners to begin the process of gaining a deeper meaning of the impact of illness and making sense of surviving breast cancer and living a full life.

Making Meaning of Illness and Survivorship

Overall, the women and intimate partners in this study managed their quality of life quite well. Each couple made adjustments to their environments; marriages; close

relationships; and physical, emotional, and spiritual health. The couples survived breast cancer, maintained their wellbeing, and strengthened their relationships by accessing their resiliency as a powerful family system. The subsequent excerpts expand on the couples' journeys of pressing through together and shed light on their reflective process of survivorship.

Introspection and Reflection As a Couple

The participants shared that taking the time to reflect upon their journeys led them to value what is important to them and their significant others. Throughout their interviews, the couples were able to pause and reflect on how their perspectives changed because of the impact of breast cancer. The couples reported how the celebration of life, normalcy, value of time, conceptualization of illness, and acts of kindness were all key in releasing the past and embracing the future. The following excerpts highlight those shared experiences of reflection and introspection for the survivors and their intimate partners.

Celebration of Living and New Normal

The excerpts below capture how the couples celebrated their treatment milestones. Their new perspectives show that living each day to the fullest is an absolute must. Not only did the celebratory experiences make those experiences special, but they also impacted others who were connected to them. Danielle found joy in her connections with others during chemotherapy treatments and shaving her hair to celebrating the end of treatment with a graduation. The following excerpts show how she transitioned from patient to survivor by embracing her process and celebrating those moments.

Danielle and Sara.

Danielle: Yeah, nothing is important as living your life . . . like I want do this today. Do I have some vacation time? You know, I have some vacation time . . . Is there money to do it? Yeah, there is some money to do it . . . okay let's do it. You know, I actually went to my boss this week and I have five vacation days left and he goes, "Are you going to take them?" and I said, "Yeah." He said, "Good, you take them . . . you might as well take them," and I feel no guilt at all about taking them. Not at all. They're my days. I earned them . . . I'm taking them. What am I going to do? I don't know, but I'm taking them. . . . If it's a nice day, I'll go ride my motorcycle. . . . If it's not a nice day, I may go to the movies. I don't care, I'm going to take them . . . they're mine. It's my time, and like [Sara] said, "Okay, we need a vacation. Let's take one," or "Let's go walk the dog." Screw guilt. Screw guilt. . . . Guilt does not have a place in my life anymore.

Sara: I told her, I said, "How about I sing you pomp and circumstance on your way out? [Graduation: Last Day of Chemo] "No!" she said. "I don't want any mess. . . . Don't do anything." There is a two-part story to this. Although I have a music degree from my undergraduate, I cannot sing a note . . . I'm horrible. So . . . whatever it was, I can't remember what day of the week, but I called . . . ordered a big bouquet of flowers and had it delivered to radiology the night before, so when she came out of radiation treatment it was sitting up there. I had gotten balloons . . . I had everything there, and everyone was in on it. . . . When she came out of the radiation center, there I was [humming pomp and circumstance]. You know it was just this big to do and the other patients . . . it was amazing

. . . how much they got out of it. It really made a difference in that room. That's a thing to do as well: celebrate every moment you think you can celebrate.

Danielle: Definitely make time for each other . . . I mean some of the best parts (laughter) . . . it may sound strange, some of the best parts of going through chemo . . . was the fact that Tulane would let people come in with me. You could have a family member or friend sit next to you . . . while you're going through treatment. I mean, that was wonderful . . . I mean, we talk [family, friends, or other patients] . . . we would talk to each other and tell each other what we were going through. . . . We were there from . . . you know. . . . We did make a celebration out of every milestone. When I started losing my hair after my second chemotherapy treatment, we arranged for our friend who is a hairdresser to shave my head. When we arrived at the salon, a number of our friends were present to watch. They bought sparkling grape juice to help celebrate and [Sara] shaved her head at the same time . . . to show her support.

Value of Time and Milestone Moments

In addition, the next excerpts express how the shift in perspective allowed the couples to gather their thoughts, appreciate their normal day-to-day activities, and look forward to enjoying future family milestones. It was important for the couples to have normalcy in their lives and enjoy the special moments shared with one another and their other loved ones.

All of the couples in the study are in long-term relationships and have gone through several life transitions together. Illness became one of those life-changing events in their lives but each couple made it clear that it did not deter them from looking forward

to living. Several couples shared during their interviews that the value of time was essential in their relationships. Being able to reclaim the simple things in life was also vital for them.

With the scare of breast cancer, the couples realized how important it was to share and create more memories as a couple and family. Most of them had extended families and had plans to attend major occasions like graduations, weddings, and births of grandchildren. The following excerpts demonstrate those various moments of valuable time and priceless memories.

Lori: I think we are different. . . . I mean, obviously we are different . . . but I think that I learned also, and in his way . . . he has changed too. He has grown now. . . . I think he is much more conscious about life, about the value of time . . . value of good times. I mean, that's something that I think that sometimes . . . we might not be as conscious as before. . . . Sometimes he forgets too. (Laughter) Is it a problem that the house is not organized at this moment? I mean, could we go five minutes later or five minutes sooner? I mean, it doesn't matter . . . it doesn't make a big deal. . . . We went to the beach. . . . We went to places because physically I could, and everything. . . . We tried to assure them [children] that our life was going to be normal.

Madison and Kasey.

Kasey: You almost kind of chuckle when I hear some people complain about their problems. . . . If you only had gone through what we had gone through. You almost have to laugh. . . . If you cannot handle that . . . what would happen if something major would happen.

Madison: I'm hoping I get to see my son graduate from high school, and my daughter has two more years . . . graduating from college. I'm hoping that I will be able to see that. . . . I do take every day as a gift . . . but I don't look too far in the future like he [husband] does. You know . . . I am able to go to my doctor once a year. I will be able to go every year, because I still go every three months. . . . But I was on Tamoxifen, so I don't have to see my oncologist every three months. Will not keep me reminded every three months that . . . I know you had cancer.

Kelly and Greg.

Kelly: It was a long journey, and I wanted to be normal . . . because you wonder. Is there life after this? I kept my practice. I was very tired. . . . I would go to my office and I would see someone [client], and then I would lie down on the couch. Then I would see someone else, but I didn't want anyone to know . . . because I was afraid. If they knew they would consider me . . . I don't know, damaged . . . not smart . . . or they wouldn't come back to me.

A few survivors expressed that they gained a broader understanding just by participating in the interview with their intimate partners. They shared that the interview was a helpful tool to address, reflect, and share how they were able to get through the process. The couples acknowledged that now they were living healthy and fulfilled lives as survivors of the illness. It created space and allowed them to gather their thoughts in a way that they had not necessarily done prior to the interview. Several couples shared that the sacredness of the interview time granted them permission to recall and articulate how they maneuvered through their cancer journey.

Conceptualization of Breast Cancer

The following excerpts highlight how the couples made sense of those life-altering moments in the middle of the interview. Lori found a way to externalize the cancer by viewing it as something outside of herself. Belinda was able to conceptualize how cancer affected her and gained insight on multiple levels. Both women were able to connect the dots and put breast cancer in a place that allowed them to move forward in their lives.

Lori and Alberto.

Lori: It's important to identify this cancer experience as something . . . that is outside of the couple . . . in a sense that . . . even though it might and it will impact the couple. It is not the couple . . . I mean it is not . . . the couple has many other things that it is not around the breast cancer.

Belinda and Kyle.

Belinda: You [researcher] have helped me to re-conceptualize some interior changes . . . perceptions . . . perspectives . . . feelings . . . that I had, and it helped me articulate them.

Acts of Kindness

A few couples also shared how their new outlook created opportunities for them to give back and express acts of kindness. Conversely, the couples expressed how they learned to accept assistance from others. Some of the women expressed that at times they felt helpless because of the illness; they just did not feel like themselves. Because of the health changes, they were challenged at times to remain active in their communities and, on some occasions, their careers. Although the women were not always in cheerful spirits,

there were incidents that created shifts in their perspectives. A common response would have been to hide their vulnerabilities and not ask for help, but the supportive nature of their intimate partners, family members, and friends made the difference. The women and her significant others felt secure and opened themselves up to receive assistance. They also found time to reciprocate that kindness and help others. There were many acts of selflessness displayed through the various experiences shared in the interviews.

The positive exchange of giving and receiving gave the couples a true offering of gratitude and acceptance. One heartfelt example of this came from Kasey, Madison's husband, who found his voice in sharing his experience as a spouse and caregiver. He expressed that the genuine gift of sharing his story allowed him to connect with other significant others. Each excerpt exhibits the respective couples' unique ways of giving back or being open to receive help. Belinda found that she undervalued her abilities and discovered that giving to others was a powerful experience. The following excerpts share how the couples' experiences touched them and those connected to them.

Belinda and Kyle.

Belinda: I think I have become . . . I think more aware of both my helplessness and my ability to help . . . really help. I don't like the word help, because as a therapist, I believe that I facilitate. I think perhaps I undervalue the power of that process . . . my ability. I also never thought of myself of having the ability . . . to really do much for anyone else other than just who I am innately . . . through this "pay it forward" process. . . . I see how powerful one single act can really be.

Danielle and Sara.

Danielle: As a couple . . . let other people help you. Let family members . . . let your friends . . . let your neighbors help you. And if people say . . . this is one thing I think freaks out people, but it make them feel good. If someone would ask me, “If there’s anything you need . . . just let me know?” A lot of people say that right . . . let them.

Sara: Yes, that was a big one [receiving help], being self-sufficient about everything . . . to allow her to come in and acknowledge that I couldn’t do it alone . . . you know. So asking people for help and accepting when they offer something was a big piece for me . . . but it was very much worth it.

Madison and Kasey.

Kasey: It was hard . . . because I was standing on a stage in front of hundreds of people. . . . It was difficult, but it was interesting because . . . it connected me with the audience. There were a number of people . . . husbands in the audience . . . some had lost their spouse to cancer and some were survivors, but you could see the connection. So . . . it was nice. . . . It’s a really nice speech. . . . It’s very emotional . . . very heartfelt.

Concluding Remarks

In this research study, I wanted to discover more about the experiences of breast cancer survivors and their intimate partners. I sought to learn how the experience affected them and how they recreated their relationships and their way of living. My hope was to examine how the experience of breast cancer revealed changes in the participants’ relationships with themselves, loved ones, and breast cancer. I hoped to gain insight

about not only the challenges, but also the positive aspects of having and surviving breast cancer.

Through the process of interviewing the participants and completing the data analysis, I knew I would have to become fully immersed in the process. By doing so, I was able to capture more understanding and meaning of the participants' shared experience of surviving breast cancer and living with the possibility of recurrence. During the analysis, I was reminded of my experiences with families I saw in therapy that managed life-altering illnesses. I also recalled my personal experiences of illness within my family. It reminded me of the complexity of illness and how it brings about sudden changes in the lives of those connected to the person who is ill. Even though there were noticeable common threads among the couples' experiences, there was uniqueness in each of their narratives.

I am truly grateful to have had the honor and privilege to interview each couple for my research study. My perspective expanded, and I was able to genuinely listen and learn from all of the couples. Each couple shared honest and heartfelt reflections. There seemed to be a level of comfort and easiness in connecting with each other, even though we discussed experiences that affected them on an emotional level. I can truly say this connection was evident during the interviews as we talked, listened, reflected, laughed, and even cried together as they shared their stories.

As a researcher and therapist, this study taught me the value of being passionate about my work and of remaining curious about the perspectives of others. I feel I have a better understanding about the lived experience of couples managing breast cancer and surviving it. Prior to completing the research, I had a limited epistemology about illness

and families from researching the topic and seeing cancer patients in practice. However, the experiences through this study have challenged me to think differently by being more curious and collaborative with families dealing with chronic illness. It confirmed how significant it is to continue to discover new things from others—personally and professionally.

In Chapter V, I discuss my thoughts and the results of the findings, and also compare and contrast the findings of this study with those in the current literature. In addition, I discuss how the results of the present study can be useful to the field of medical family therapy.

CHAPTER V: DISCUSSION AND IMPLICATIONS

“When we can be wholehearted, we welcome everything.

Then, the journey is to see how everything goes together and works together, no longer choosing one way over the other.”

M. Nepo (2013, July 1). Where paths meet. Retrieved

from <http://threeintentions.com/2013/07/>

When I begin to reflect upon why I chose this topic for my dissertation, I still have feelings of enthusiasm. I can vividly recall the moment when I decided on the research topic of breast cancer survivorship. It was clear that I wanted to capture the experiences of families’ perseverance through survivorship. I was aware of the partner bond that occurs during diagnosis and treatment phases but was curious about the post-treatment phase of surviving the illness.

In the summer of 2012, I completed a research internship under the supervision of Dr. Tan-Chiu. Dr. Tan-Chiu is a medical oncologist in the South Florida community who specializes with breast and ovarian cancer patients. She is very passionate and dedicated in her work with women helping them to survive and live full lives beyond their gynecological cancer. I admired her compassion and knowledge when she interacted with her patients and loved ones during their doctor visits. She encouraged her patients to be well informed and an active part of their treatment and survivorship process; I very much appreciated her approach. By witnessing those intimate interactions, I observed and listened not only to the doctor/patient conversations but also to the patients and their loved ones as they shared their personal experiences. Women and their loved ones were

very open about their experiences and how they were able to successfully beat their cancer and live healthy and fulfilled lives.

Those experiences propelled my research ideas and my curiosity to gain more insight and knowledge. I hope to expand how therapists and physicians could implement helpful resources due to a better understanding of the couples' needs. There is a dearth in current literature that examines the experience of survivors and their committed partners and how they survived breast cancer. I want to utilize my dissertation research as an additional stepping-stone to provide new perspectives in breast cancer survivorship research.

There are times when I questioned myself for using a systemic versus individual approach to breast cancer research because I chose to focus more on the couple's experience of surviving rather just the women's experience. With positivity and patience, the process unfolded over time. This research study was very personal to me and I believe it reflects my values and importance of relationships, cancer research, and therapy. I have been incredibly honored and blessed to listen and learn from the five couples that willingly shared their life experiences with me.

In this chapter, I highlight the reported experiences of the couples and compare these to the extant literature. In addition to that, I offer my personal reflection and thoughts regarding the couples' experiences and how they manage uncertainty and the possibility of recurrence. Next, I discuss limitations and implications for the study. I will close with my final thoughts.

Discussion of Study and Findings

In this phenomenological study, I examined the lived experiences of five couples that survived breast cancer. The goal of the study was to capture how they make meaning and cope with the changes that occur in their relationship with themselves, their loved ones, and the illness itself. The study was not limited to the diagnosis and treatment, but focused more on their experience of survivorship and the possibility of recurrence.

To date, there are only a few studies that have examined the post-treatment experience of survivorship and uncertainty between the survivor and her intimate partner. The lack of research might be due to the difficulty in finding participants to share their intimate experiences or even the perception that only the breast cancer survivor is impacted by this life-altering illness. However, the couples in this study had a great deal of information to share regarding their relationships, the stressors they managed, and how they were able to live beyond breast cancer.

All of the couples shared some positive changes in their lives even though cancer impacted their lives. Each couple found it important to share detailed accounts of their initial diagnosis. The women and their intimate partners were able to willingly share their emotional responses and the impact on their loved ones. They shared exact details when she received her diagnosis. The breadth of their descriptions and openness allowed me to better understand and appreciate their accounts. As I completed the review, I begin to brainstorm how I would bring everything together. I am a visual person so I created a simple system to organize my transcript, which I discussed in the previous chapter.

Each couple that participated in the study was actively involved and genuinely interested being apart of the research study. The interviews all lasted a minimum of one

hour; the longest interview lasted an hour and a half. Four of the five couples reviewed the transcripts and provided minor corrections as well as additional comments. All of the couples supported my hope that by sharing their experience of surviving and living beyond breast cancer would help others. My impression is that the couples enjoyed our conversations and even seemed surprised at the easiness and natural flow in our shared dialogue. Speaking openly with me about their experiences as a couple surviving cancer together appeared to be good for them. Several of the couples shared that the interview was a reminder of what they accomplished together. For me, it confirmed that illness impacts those closely connected to you and that having a supportive intimate partner not only strengthens their relational bond but improves overall well-being. It can be quite difficult to have conversations about how one overcomes cancer and manages the possibilities of recurrence. One study endorsed that communication about cancer related concerns between phases of illness can become inconsistent and decrease over time (Henderson, Davison, Pennebaker, Gatchel & Baum, 2002). I acknowledge that most couples would not have open conversations about their experiences of managing such an illness. Combating the stigmas of breast cancer could possibly lead to these discussions because of fears or feeling uncomfortable about re-visiting such a life-altering change in their personal lives. However, it seems that these perceptions make it difficult to educate or even invite others into conversations about breast cancer and survivorship.

A recent Associated Press article discusses cultural influences on women and cancer, particularly addressing breast cancer taboos. It highlights how Pakistani women who are a part of conservative, Islamic cultures cannot talk about their breast cancer because of its association with sexuality rather than health. Culturally, it is viewed to be

immoral to seek breast exam screenings or even discuss with their families. My initial response to reading the article provided me with more awareness. I reflect back to a few telephone calls during my initial pre-screening interviews. Each of the women was excited to contribute to my research and willing to share her experiences with me. Unfortunately, they did not meet criteria and had recently separated from their intimate partners due to the impact of illness on their relationship. I remember thanking them for contacting me and sharing their interest and willingness to participate. Personally, I checked in with them about their support and they expressed they had strong support systems, I inquired about their support because I genuinely care and I understand how chronic illness can impact a person without supportive and genuine connections. I cannot imagine how devastating it would be to live in a culture that does not support one to openly communicate about their illness experiences with loved ones. However, I understand this may not be a common story of women living among our Western culture. I acknowledge the luxury of having conversations to process those experiences with an intimate partner. I hope that my research will create dialogue about initiating a change for women and their loved ones regarding how we understand the experiences of breast cancer survivors. With more research, we, as family therapists, can create opportunities for more support and resources during post-treatment for this growing population.

Discussion of Categories

The themes presented in the previous chapter emerged from the couple interviews in this research study and capture the experiences of breast cancer survivors and their intimate partners. I discuss how the themes in Chapter Four compare to current research literature. I inquired about the participants' experience of overcoming challenges during

their illness experience. Their initial response to the impact of diagnosis, treatment, and survivorship was different for each couple. There were variations in their responses not only in their experiences but the severity of their breast cancer, family history, and likelihood of recurrence. I believe this impacted how the couples managed their perception of breast cancer after they survived. Nevertheless, each participant's understanding of breast cancer evolved after reaching survivorship. When I asked questions about differences they noticed in themselves, the participants' responses described a change in their outlook. Relationships, beliefs about spirituality, and their futures were all examined during this stage in their lives. It was apparent that the couples pressed forward by relying on each other, extended support, and resources. The couples' resiliency and strength flourished and allowed them to overcome any stressors that arise. The couples grew stronger within their marital relationship, communicated more openly, and celebrated living by surviving their experience together. The participants' experience align with the results of this qualitative study (Skerrett, 1998), that the couple's ability to manage the complexity of their experience, co-create meaning that they can move forward with, and construct a plan of action for continued adjustment makes a critical difference in their relationship and survivorship.

Emotional and Psychological Responses

The results of this research study indicate the survivor and her intimate partner were both affected emotionally and physically due to the impact of illness. The findings seem to closely support the results of researchers (Schmallling & Sher, 2000; Thorne & Murray, 2000), that breast cancer survivors' experiences are not physically and emotionally isolated. A study conducted by Mellon, Northouse, & Weiss (2006), found

that when the survivor's quality of life was improved the partner's also improved. In addition to that, survivors reported less fear of recurrence than their intimate partners.

In this research study, the participants' narratives supported the idea that those closely connected to them during this time of transition and phases of uncertainty were impacted both emotionally and psychologically. The couples from the study did not describe much fear with regards to the possibility of recurrence. Some of the couples did report heightened anxiety or worry around certain scheduled doctor follow-ups or even catching a common cold. For instance, Kelly and Greg shared that processing with one another prior to appointments eased their worry and anxiety. In other words, survivorship did not exclude feelings of uncertainty that occur even after completed years of treatment (Shaha, Cox, Talman, & Kelly, 2008). Uncertainty could possibly account for various stressors connected to the long-term effects and risk of secondary recurrence. It's clear that the survivors and their intimate partners' concern or worry progressed beyond diagnosis and treatment; it affected the couples even in post-treatment.

Physical Responses

The process of diagnosis, surgery, and treatment can impact the couple emotionally as well as physically (Skerrett, 1998; Thewes et al., 2004). Women report changes not only in their physical appearance but changes in sexuality, impaired cognition, fatigue, and decreased physical functioning (Ganz et al., 2002; Ganz et al., 1998; Leventhal & Shearer, 1989; Thewes et al., 2004). When I inquired about challenges due to illness, a few couples described how there was a complexity of multiple physical changes happen all at once. Each couple had to find a way to manage the impact of the breast cancer along with each other's additional health concerns. I did not find any

literature about the complexity of multiple illnesses and impact on the couple after breast cancer and/or survivorship. However, as the researcher it is apparent that the couples were understanding and compassionate towards one another in dealing with their physical challenges.

Financial Responses

Couples can also be impacted greatly from the financial burdens during this time (Hoffman, 2002; Tesauro et al., 2002). Financial challenges can arise because of issues with insurance, loss of job, or even limited funds because of changes in work schedules (Tesauro et al., 2002). One study suggested that changes in employment status (retirement, change in type of employment, and decrease in work hours) could potentially create more challenges for them (Hoffman, 2002). Several couples in this study expressed how financial burdens were present because of the complexity of multiple illnesses in their relationship. Belinda and Kyle shared how they were impacted tremendously because they lost both sources of income. They shared in their interview how people from their local community blessed them with financial gifts. Eventually, they were able to restore their health and began working again. Their financial hardships were unfortunate challenges but they persevered. Unfortunately, literature seems to be sparse in the area of financial stressors among breast cancer survivors. I did not find any current research that addresses how financial challenges impact the survivor and intimate partner relationship.

Support and Resources

The findings of this category support the current literature closely but with a few limitations. The couples' relationships, their network of family, friends, and neighbors

were important in acquiring a healthy quality of life and successful transition into survivorship. Receiving emotional and practical support from spouses, children, parents, extended family members, and even friends was helpful for the survivor (Thewes et al., 2004). Each couple shared multiple times throughout the interviews how they acknowledged and valued their support systems and resources. Not only were they available for one another as couple; loved ones supported them. During the interviews, I asked about the role of psychotherapy and/or support groups and how that may have changed their relationship and survivorship experience. Support groups and psychotherapy were reported as additional resources that were recommended or at times used by the couples in this study. Current research shows that psychotherapy, or counseling, have become more popular in the treatment of cancer survivors (Ganz et al., 2002). Research shows that more than 13% of the women in a quality of life study utilized counseling services, and others reported that they used psychotherapy in the past (Ganz et al., 2002). However, the women and their intimate partners shared that they did not find that using psychotherapy and/or support groups was as helpful as they anticipated. For example, Belinda and Kyle attended a few couple sessions and did not find it to be very helpful. In fact, they contributed their successes to doing therapy on their own. The couple are both therapists and they expressed they had the clinical skills to manage their stressors together. In contrast, Lori attended psychotherapy soon after her diagnosis and found that she was able to handle her illness better because of her sessions. Belinda and Kelly, shared that they had negative experiences attending breast cancer support groups. Both women felt that they were more in a role of group facilitator than actually receiving support from the group. Interestingly, a new finding in the study

showed that the intimate partners were not offered support services. Some intimate partners shared that they attended support groups or even therapy sessions occasionally with their spouses. There seem to be limited resources and support offered or possibly poor delivery in availability of resources for intimate partners.

Strength as a Unit

Emotional support and communication were important aspects that enhanced the adjustment and relationship quality among the couples in the study. Their ability to utilize self-disclosure of their thoughts, concerns, and emotions resulted in a healthy and strong relationship bond. Using these relational strengths as a couple played a big role in the participants getting through the diagnosis, treatment, and now survivorship.

Those aspects were consistent with a research study conducted by Manne and colleagues that found that sharing one's thoughts and feelings towards one's spouse improves their intimacy and ultimately strengthens their relationship (Manne, Ostroff, Rini, Fox, Goldstein, & Grana, 2004). Several of the couples in my study shared that their relationship benefited greatly during the life-altering change but they did acknowledge that there were obstacles at times. They expressed that their relational strengths were improved or even re-confirmed during this challenging time. Even though several of the couples were able to manage stressors on their own, some of them sought additional support from others. Research shows that seeking social support and emotional support is useful and provides a better quality of life (Mellon et al., 2006), thus affirming why the couples were able to adjust and manage their challenges so well together.

A research study conducted at Ohio State University showed a correlation between women in unhealthy marriages and health concerns. The study examined 100

women with breast cancer and the researchers showed that those in bad marriages fared less than those in happy marriages. In fact, another study conducted by University of California, San Francisco, examined the social networks of 3,000 nurses with breast cancer. The data showed that women who went through breast cancer alone were four times more likely to pass away from illness than women with a network of ten or more loved ones supporting them throughout their cancer journey (Kroenke et al., 2006). The study also suggested that friendships might have more impact on health than having a spouse. The study did not show a significant benefit in having an intimate partner but having several friendships did. So it seems that women who have socially rich relational connections cope better than those who do not.

In certain cases, spirituality and faith played a role in restoring the participants' hope in overcoming their illness and living full lives. It also offered them support of a larger community that shared the same beliefs. According to Pollner (1989), people with faith in a higher power are more likely to have better health benefits. Researchers reported that being open to spirituality would likely improve one's coping with illness as well as enhance quality of living (Broeckel et al., 2000; Burstein et al., 1999). Several couples in the study shared how their spirituality helped them find a deeper meaning of their purpose in living and even improved their closeness as a family. Kelly and Greg reconnected with God during this time as a couple. Lori found that through her spiritual connection she was enriched and empowered. Belinda discovered a new way of connecting spiritually that encouraged her to help others. Overall, the participants found unique ways in which they were able to connect to something greater than them and found peace in doing.

Introspection/Reflection as a Couple

The women and their intimate partners in this study managed this life-altering change well. The participants took time to reflect on how their perspectives changed because of the impact of breast cancer and their desire to live beyond cancer. I inquired about differences they noticed in one another and what things helped them to cope during this time. The couples reported the desire to find a sense of normalcy again and find purpose in this life-altering change. The couples shared how they began to find meaning by gaining a new perspective in living. The women revealed that they became more involved in making memories with their family members and continued to do activities together like any normal family.

Another result was that the couples were willing to convey their stories about treatment, survivorship, and how they make meaning of living with the possible recurrence. The results of this theme aligned closely to the research study of Kissane et al. (2011) who found that the ability to find meaning in the cancer experience can help couples cope better with the illness. Meaning making was a significant finding among the couples' narratives. Each dyad was able to openly engage in insightful conversations during various phases in the cancer journey and shared that it was quite helpful in coping with illness and possible recurrence. One of the survivor's, Lori, words encapsulates one's ability to find meaning in illness. She stated, "I think we are...I think we are much more conscious about life, about value of time...value of good times." Others even shared that the interview time allowed them the space to reflect differently about their experiences. For instance, Danielle, Sara, and Lori shared how having additional

psychosocial support through therapy and support groups offered them more insight in how to cope with treatment and survivorship.

Implications of the Study

Even though the ten participants survived the breast cancer experience in relationship with their respective partners, each couple varied in terms of their personal beliefs, meaning, and context of the journey. Each couple, even each individual found different experiences to be meaningful. These differences offered a broader understanding of a shared, lived experiences with rich accounts in how each person found meaning and coped with the changes in their lives.

Although this research study was designed to address the gap in literature regarding the breast cancer survivor and her intimate partner at the time of survivorship, there were several limitations that should be considered when examining the research findings. I discuss how those limitations can improve with further examination through continued research and practice.

Strengths and Limitations

Using qualitative analysis for this research study provided the participants to have an actual voice in sharing their experience of how they dealt with survivorship and uncertainty of possible recurrence. More specifically, IPA focused on the couples' personal meaning and making sense of surviving breast cancer and living beyond that experience of illness. The sample was generated through purposive and convenience sampling. Participants were invited to the study through word of mouth, sharing flyers with colleagues, cancer survivorship support groups, and physician referrals. It is quite possible that participants in the study were better adjusted and had a more positive

outlook on their breast cancer. On the other hand, participants who tend to worry more or have feelings of dissatisfaction in their relationship may have chosen not to participate in the study. The selected participants' educational background, accessibility to resources, and financial status could have all been variables towards better coping skills and perspectives in surviving breast cancer. However, the study would have benefited greatly from a more diverse group of participants. It might have been useful to connect with the national cancer registry and/or major cancer research hospitals for potential participants.

Secondly, the sample was relatively homogenous in regards to various factors, such as age (mostly middle age population), mainly Caucasian-American, higher education (seasoned therapists or completing degree in family therapy), and with middle class income. It was a coincidence that most of the participants identified as a part of the field of marriage and family therapy. Each of those factors could have led to less variability within the sample and possibly less uniqueness in the participants' shared experiences. The level of their resources could have also affected their success in managing their survivorship because the participants may have been more educated about their illness experience and more equipped to tackle their medical needs towards survivorship. Also, income levels may have afforded them access to excellent medical care that might not be so readily available to the general population.

Third, participants may have answered their questions in a socially desirable manner. For instance, participants could have answered their questions in a way that expressed more positive responses than reporting any dissatisfaction, worry, and/or uncertainty in their relationship. Couples could have responded in this way to avoid

conflict in their relationship or even to reflect desirable answers as part of their role in this research study.

Fourth, the length of time since treatment and total number of years as a survivor varied within the sample population. Some of the participants had experienced living cancer free for almost 13 years post-diagnosis. In addition, the women varied with being in different life stages. For example, some women reported having adult children and grandchildren to waiting for their youngest children to graduate from high school and attend college in the near future. Also, there was variability in other life transition stages such as entering retirement to graduating from university as non-traditional graduate student. Because of these variations, the participants might have reported differences in how they manage illness and stages of life.

The last limitation was the sample size of couples in the study. I did meet the proposed number of participants for this qualitative study. Although the previously mentioned factors were all possible limitations in the study, I often wonder if the sample size was too small or not diverse enough to determine similarities and differences to accurately analyze the data. Determining an adequate sample size in qualitative research study is important to capture not only the quality and thoroughness of the topic (Smith, Flowers, & Larkin, 2013). It's important to explore how the previously discussed limitations and this type of research can be improved with further qualitative study.

Validity and Reliability

There are four key principles that measure the quality of qualitative research. Yardley (2008) clearly addresses that the first principle is the "sensitivity of context" (p.180). Throughout the research study, I was conscious of being sensitive to the

information shared regarding the participant's experiences about going through illness such as breast cancer. I was very selective about the questions I asked. I expressed that I respect how much or how little information they wanted to share with me regarding their experience. In addition to that, I remained sensitive to context and how questions were presented and asked during the actual interviews with survivors and their intimate partners. I consciously remained respectful and empathetic during the interviews. It is important to be sensitive with questions asked and to honor the participant responses by reporting their desired accounts in the research study.

The second principle is commitment and rigor. I was committed to being attentive to the couples' needs during the initial screening process, interview, follow-ups, and data analysis. It was important to be aware of their comfort level in what they were sharing with me through their interview. I also carried the same level of commitment when developing and organizing the data analysis. Sensitivity of context and level of commitment join together to honor the participants' experience in this research study. Equally important was the additional principle of rigor. From the beginning of study, I carried the values of producing quality research that included good interview experiences and through data analysis. I worked closely with my dissertation chair, Dr. Shelley Green, to compile open-ended questions that were respectful and allowed the participants room to address the questions in a way, which they were most comfortable. I clearly stated at the start of the interview process that the participants were to interrupt me if any of the questions or the direction of the interview was not comfortable for either one of them. I carried that same set of values when I began to analyze the raw data. Dr. Green supported

me greatly throughout this process and advised me to ensure that my research project met those standards.

The third principle of Yardley (2008) is transparency and coherence. During this process, personal pieces of the couples' lives were shared based upon questions, thoughts, or even recalled memories. I had to be clear about my goals for the research and clearly document each stage of the research process. I assured that both transparency and coherence were shown through the descriptions from the selection of participants, compiled interview questions, and steps of the data analysis. I wanted the reader to have an insider's view of my experience and process as the researcher. Throughout the drafting and re-drafting process, I was able to find coherence between research questions of the study and sought to make sense of the participants experience as couples who survived breast cancer. The final principle of Yardley is impact and importance. My hope is that the reader will learn something new and expand their awareness and understanding by reading this study. This project should challenge not only therapists but also other medical professionals who desire to effectively work with this special population. This valuable information should aspire others to learn more about support needs of breast cancer survivors and their intimate partners.

Implications for Practice and Research

Implications for Practice

When addressing the impact of cancer, its typically viewed from an individual lens from the perspective of the woman who has been diagnosed, gone through treatment, and is now in remission. Given the uniqueness of the intimate partners' experience from this study, both in the treatment and survivorship stage of breast cancer, it is clear that

partners should be participating members in the illness experience itself and engaged in the current research on the subject. Information, therapy, support groups, and other additional resources should be provided to both the survivor and her intimate partner as a unit rather than individually. It's not surprising that literature reports that the partner's uncertainty and anxiety can be heightened during treatment and post-treatment phases for the breast cancer survivors. Many oncology treatment centers have resources available or referrals for the survivor to attend support groups or counseling during their experience. Some medical practices might not have clinical support staff and resources to share additional referral information to patients.

The same is not offered for intimate partners going through this experience. Often, intimate partners are present during doctors' appointments, chemotherapy, surgery, or even follow-ups where the focus is not always on the couple but most likely the individual patient. Even though, the oncologist, nurse, or social workers working in various hospitals and agencies offer caregiver support group materials and support information it's often more directed to the patient than survivor. Therefore, both medical family therapists and oncologists should work together to create a way to address the disparity of not having consistent available resources or continued care after survivorship within this special population. As systemic thinkers, family therapists have the expertise to address the relational challenges within systems. Often, physicians and even patients are not aware of the support that we offer as family therapists. We can easily support and facilitate in managing the changes due to the illness. Therapists can fill the gap of addressing how attending therapy and learning coping skills can be helpful not only for the individual but the intimate partner going through this experience with her.

Results from this study have confirmed the importance of communication and emotional support as two factors that influenced positive coping and adjustment for the couples. As family therapists, we can assist couples that are transitioning to life after treatment and who are grappling with the challenges of uncertainty and moving forward in their lives. Medical and clinical professionals can collaborate and develop ways to influence positive changes in the couple experience of illness. For example, professionals could begin to assess the strengths and coping skills of the survivor and her intimate partner during post-treatment follow-ups. This type of assessment could be gathered during routine oncology visits or even in survivorship group meetings as well as counseling sessions. Having worked in a systemic medical practice, I believe that collaborative treatment could become quite helpful for patient as well as medical staff involved in the continued care for the patient and her loved ones. Practitioners can easily assess and identify any stressors and then the family therapist or physician could help the couple to find additional resources to better cope. Assisting the couples to seek emotional support during actual doctor appointments or follow-up calls could be another example of identifying how assessment could be useful during routine visits with survivors. Making the connection to see a therapist can facilitate conversations that allow them to openly discuss their concerns or fears with moving forward effectively. The participants in the study noted that psychotherapists, social workers, as well as physicians during their treatment/survivor journey should be more sensitive to listening to the survivor and her intimate partners. Several of the participants shared how a mutual respect of their personal knowledge and related questions was helpful in building a relationship with their health care provider. As medical professionals, it is important for us to listen to the

couples' concerns and collaborate with other medical professionals to effectively address the survivor and intimate partners' needs.

Furthermore, open communication was reported to be as helpful as emotional support for the sample population in the study. The couples reported how communication made a difference in their experience because they were comfortable sharing their fears and vulnerabilities with one another. They also expressed that they respect each other's emotions. I recall from interviews that several couples utilized this tool through letter writing or just by setting aside a special time during the week. This experience provided the couples a healthy outlet to express themselves and time to listen to one another. Clinicians could encourage couples to set aside a time during the week to reconnect and check in with one another between health care visits. While these are only a few examples, they may serve as stepping-stones to address additional ways in managing the adjustment and challenges. By initiating dialogues, medical professionals could create additional skill sets that couples could utilize not just for managing breast cancer but also other types of cancer and chronic illnesses. As family therapists, we can work together and explore more about shared understanding, open communication, and coping mechanisms through continued practice and research.

Implications for Research

Future research might start by addressing the limitations of the study. The two important factors to address would be sample size and diversity of sample population. If future studies could increase the number of couples while at the same time increase the diversity of participants, the effects of survivorship and uncertainty could become more distinct. Minority groups were under represented in this study and their diagnosis,

treatment, and survivorship experiences should be examined to better understand and improve the implications for research as well as practice.

Although there were significant challenges expressed among the participants in the study, uncertainty did not play a major role in breast cancer post treatment because of the participants' ability to make sense of and draw support and resources to get through this experience. So, the question is how do couples without those abilities get through this life-altering change? I firmly believe that the participants in this study were well equipped to handle their challenges because of a strong foundation and commitment to their relationship. The couples each had strong values and beliefs about relationships and change. However, I am aware that not all couples successfully endure the challenges of surviving illness and maintaining a healthy marriage. This does suggest that researchers need to further explore the experiences and belief systems of the couple within this phase of survivorship. Recent literature is still sparse involving the breast cancer survivor and her intimate partner in general and more specifically, post-treatment. Future research must continue to examine the uniqueness of the dyad going through diagnosis, treatment, and survivorship together. Uncertainty in illness can be a complicated experience and continuing to explore the experiences of the couple through qualitative research is beneficial. Further insight can continue with qualitative studies that ask more questions centered around individual experiences and those as a couple, thus contributing further knowledge and understanding about couples experiencing breast cancer. In the advancement of our growing field, medical family therapists can proceed in making a difference and broaden the meaning of survivorship and the impact on the lives and relationships of individuals other than breast cancer survivor.

Final Thoughts

As treatment continues to advance in breast cancer, couple survivorship will continue to grow. The findings of this study suggest that having a supportive intimate partner alleviates impact of uncertainty on the couple's relationship. It also highlights the importance of relationships, resources, and changes in perspectives. My intention was to present the lived experiences of couples and explore how they were able to get through uncertainty and living beyond breast cancer. I wanted to share their experiences because I believe that the audience would have something to learn by hearing another part of the survivorship story through the multiple perspectives and relational components of the cancer experience.

My purpose in life is to help others see possibilities in their lives and to embrace change in order to become better people. We all have challenges in our lives that affect us and our loved ones. It's through adversity that we understand who we are, what we value, and what is truly important to us. The couples in this study demonstrate how we can overcome life challenges by drawing upon resiliency and re-creating a life that brings fulfillment in their relationships.

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Appendix A Cancer Survivor Consent Form
Appendix B Significant Other Consent Form


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Approval Date: FEB 18 2014
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Consent Form for Participation in the Research Study Entitled
Living with Uncertainty: The Impact on Breast Cancer Survivors and Their Intimate Partners

Funding Source: SHSS Memorial Fund

IRB protocol #: 02151314Exp.

Principal investigator:
Kimberley Dockery, M.S.
6350 Cedar Plaza #113
Omaha, NE 68106
(901) 674 3929

Co-investigator:
Shelley Green, Ph.D.
3301 College Avenue
Fort Lauderdale, FL 33314
(954) 262 3028

For questions/concerns about your research rights, contact:
Human Research Oversight Board (Institutional Review Board or IRB)
Nova Southeastern University
(954) 262-5369/Toll Free: 866-499-0790
IRB@nsu.nova.edu

What is the study about?

You are invited to participate in a research study. The purpose of this research project is to convey the experiences of those surviving cancer—to share their stories of survivorship and their experiences with the uncertainty of living with possible recurrence. The researcher (principal investigator) will explore the survivors' and their intimate partners' experiences of survivorship to gain a better understanding of how their lived experiences affect their relationships to themselves and their couple relationship and how they cope with the uncertainty of recurrence.

Why are you asking me?

We are inviting you to participate because you are: adult between 30-75 years of age, diagnosed with breast cancer and currently in remission within five years prior of this study, have an intimate partner that shared this survivorship experience, English speaking and willing to participate. There will be 16 participants in this research study.

Initials: _____ Date: _____

Page 1 of 4

Graduate School of Humanities and Social Sciences
3301 College Avenue • Fort Lauderdale, Florida 33314-7706
(954) 262-3000 • 800-262-7978 • Fax: (954) 262-3998
Email: shss@nsu.nova.edu • <http://shss.nova.edu>

What will I be doing if I agree to be in the study?

As a participant in the study, you agree to be interviewed face-to-face with your intimate partner by the researcher, Ms. Dockery, about the experience of surviving breast cancer and living with uncertainty of recurrence. Participants will have the option to schedule a face-to-face person interview in a private location or Skype interview. Each participant dyad will be asked approximately ten open-ended questions in an interview lasting a maximum of two hours. You will be contacted for a follow up over the phone after the interview if further questions arise or clarification is needed. A copy of your transcribed interview will be mailed or emailed to you. You will be given one week and should spend no longer than 30 minutes reviewing your transcript. The follow-up interview should last approximately 15 minutes. I will give participants the opportunity to change any information that they believe to be incorrect.

Is there any audio or video recording?

This research project will include digital recording of the entire length of the interview. This digital recording will be available to be heard by the researcher, Ms. Kimberley Dockery, the IRB and the researcher's dissertation chair, Dr. Shelley Green. The recording will be transcribed by Ms. Dockery only and will not be transcribed by anyone else. The digital recordings will be kept securely at the researcher's office in a locked filing cabinet. All transcribed material will be kept on the researcher's office computer that requires a password to log on only known by the researcher. Your personal information will be protected by the assignment of a pseudonym on the transcribed documents of your interview. All recording material will be kept for the duration of 36 months from the end of the study and deleted. Any other hard copy identifying information will be destroyed after that time by shredding. Because your voice will be potentially identifiable by anyone who hears the recording, your confidentiality for things you say on the recording cannot be guaranteed although the researcher will try to limit access to the recording as described in this paragraph.

What are the dangers to me?

To the best of the researcher's knowledge there are minimal emotional risks associated with participation in this research study. During the interview, there is the possibility that uncomfortable issues may arise in conversations that adversely affect you. You have a right to refuse to answer any question and to discontinue interview at any time. If you need further help, Ms. Dockery will suggest someone you can see but you will have to pay for that yourself. The loss of confidentiality and privacy are other potential risks; however, specific measures established by Ms. Dockery will minimize these risks.

If you choose to conduct interviews over Skype, it is important to visit the Skype privacy policy website (<http://beta.skype.com/en/legal/privacy/>) regarding your collect of information that may be included (but not limited to) your name, address, phone number, email address, age, gender, IP address, etc. While you may not choose Skype interviews, I want to address that by participating in this study, Skype may collect identifying information.

Initials: _____ Date: _____

Page 2 of 4



Institutional Review Board

Approval Date: FEB 19 2014

Continuing Review Date: FEB 18 2015

If you have any questions about the research, your research rights, or have a research-related injury, please contact the principal investigator, Kimberley Dockery, MS, PhD Cand. You may also contact the IRB at the numbers indicated above with questions as to your research rights.

Are there any benefits for taking part in this research study?

There are no direct benefits to you for agreeing to participate in this study.

Will I get paid for being in the study? Will it cost me anything?

There are no costs to you or payments made for participating in this study.

How will you keep my information private?

All information obtained in this study is strictly confidential unless disclosure is required by law. The IRB, regulatory agencies, or Dr. Shelley Green may review research records. Further, if the researcher is under the assumption that the participant is in imminent danger to himself/herself or others, it will become the researcher's ethical and legal obligation to take the necessary precautions to protect all parties concerned. For example, reporting to law enforcement. Pseudonyms will be assigned to each participant to protect participant's private information and ensure confidentiality. All information utilized in this research project such as digital recordings, notes, and any other identifying information will be locked in a filing cabinet in the researcher office or stored on the researcher's office password protected desk computer. All information and data collection material that is obtained in this study is highly confidential and will be stored for a required 36 months after completion and destroyed thereafter. The final research report will be used for academic purposes and may be published in manner that guarantees anonymity of all participants.

What if I do not want to participate or I want to leave the study?


You have the right to leave this study at any time or refuse to participate. If you do decide to leave or you decide not to participate, you will not experience any penalty or loss of services you have a right to receive. If you choose to withdraw, any information collected about you before the date you leave the study will be kept in the research records for 36 months from the conclusion of the study and may be used as a part of the research.

Other Considerations:

If significant new information relating to the study becomes available, which may relate to your willingness to continue to participate, this information will be provided to you by the principal investigator.

Initials: _____ Date: _____

Page 3 of 4


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Voluntary Consent by Participant:

By signing below, you indicate that


- this study has been explained to you
- you have read this document or it has been read to you
- your questions about this research study have been answered
- you have been told that you may ask the researchers any study related questions in the future or contact them in the event of a research-related injury
- you have been told that you may ask Institutional Review Board (IRB) personnel questions about your study rights
- you are entitled to a copy of this form after you have read and signed it
- you voluntarily agree to participate in the study entitled *Living with Uncertainty: The Impact on Breast Cancer Survivors and Their Intimate Partners*

Participant's Signature: _____ Date: _____

Participant's Name: _____ Date: _____

Signature of Person Obtaining Consent: _____

Date: _____


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Appendix C Participant Interview Questions

Key overarching questions

- How does a couple establish a clear vision of their lives when dealing with survivorship and the uncertainty of recurrence?
- How is the couple making meaning and coping with the changes breast cancer has caused in their lives?
- What role did psychotherapy and/or support groups play in their relationship and illness experience?

Semi-structured interview questions

- What has been the greatest challenge to overcome as a couple during this journey of survivorship?
- Is there anything that specifically helps you cope with the uncertainty of cancer recurring again? Cope together as a couple?
- Did you receive a referral from your oncologist to address any stressors during diagnosis, treatment, or survivorship period of the illness experience? If so, what did of mental health professional did you see? If not, explain why you didn't follow up with seeing a therapist?
- Have you seen a therapist? If so, how was your experience? What did the therapist assist you with? Did you attend alone for sessions or with a partner and/or family members?
- If you saw a family therapist, how was your experience? What did he or she assist you with? Did you attend alone for sessions or with your intimate partner?
- Did you utilize support groups during your process of treatment? During your phase of remission? If so, how was your experience? Did you attend alone? Family? Caregiver? Friend?
- Do you see a difference in yourself since survivorship? If so, what do you see? Would others recognize that difference?
- In what ways, if any, has cancer survivorship and uncertainty played a role in how you as a couple move forward in your future?
- Would you share anything with a couple that is beginning to go through this process?
- Would you share anything with medical care professionals that managed your care during this process? Your intimate partner's care?

Appendix D Recruitment Letter

Date

Dear Participant:

My name is Kimberley Dockery and I am a PhD candidate in the Marriage and Family Therapy (MFT) program at Nova Southeastern University. I would like to invite you to participate in the research study for my dissertation entitled *Living with uncertainty: The impact on breast cancer survivors and their intimate partners*. You are eligible to participate if you are 30 to 75 years of age, are currently in remission of breast cancer diagnosis for at least five years, you can participate with your intimate partner with whom you shared the survivorship experience, and you are English speaking and willing to participate to share your unique experiences related to breast cancer survivorship.


If you chose to participate in this research study, you will be interviewed in person or via Skype with your partner about your experiences of survivorship, how this experience have affected you, your relationship with your intimate partner and how you are managing the uncertainty of possible recurrence. These in depth interviews will last no longer than 2 hours and will be audio recorded. You will also be asked to review your interview transcripts and to participate in a brief follow up interview.

I have received approval for this study from Nova's Institutional Review Board (IRB). My dissertation chair is Dr. Shelley Green (Shelley@nova.edu). If you are or know of anyone who is interested in participating in this study and for more detailed information, questions or concerns, please contact me at kdockery@nova.edu or phone me at 901.674.3929.

Thank you and I look forward to hearing from you.

Warm regards,

Kimberley Dockery, M.S., PLMHP, PhD Cand.


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Biographical Sketch

Kimberley D. Dockery was born in Memphis, TN. After completing her bachelors in psychology at Christian Brothers University, she worked as continuing education coordinator at University of Tennessee, Cancer Institute. Because of her involvement in cancer research and education, she decided to pursue her masters at Kansas State University in Family Therapy. She relocated to South Florida to complete her doctorate in Family Therapy at Nova Southeastern University.

Dockery works with an array of clients, including individuals, couples, and families. Her clinical interest includes working with clients dealing with grief and loss issues, anxiety, and adjustment issues as well as clients dealing with chronic illness. She is dedicated to facilitate positive change through exploring the client's story within their context, interactions, and relationships. She enjoys spending time with her family and friends, baking, and relaxing at the beach.